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OXFORD DOCTORAL COURSE IN CLINICAL PSYCHOLOGY

**Partners in Pain:
Investigating the relationship between illness
perceptions, psychosocial adjustment and coping in
chronic pain partners.**

by

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October 2001

**Dissertation submitted in part fulfilment of the requirements of the Open
University / British Psychological Society Doctorate in Clinical
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ABSTRACT

Objectives: To (i) assess the psychosocial functioning and adjustment of partners to living with someone with chronic pain, and (ii) investigate the relationship between illness perceptions, psychosocial adjustment and coping in chronic pain partners.

Design: A cross-sectional survey and interview design.

Method: Thirty-five partners of chronic pain patients completed the revised Illness Perception Questionnaire (IPQ-R), the Psychological Adjustment to Illness Scale (PAIS-SR), the COPE, the physical functioning scale of the SF-36 and the somatic subscale of the GHQ-28. Ten partners also took part in semi-structured interviews. Stepwise multiple regression analyses were used to examine whether partners' illness representations explained more of the variance in their psychosocial adjustment and coping than demographic and disease variables. Interview data was analysed using grounded theory.

Results: Results indicated that living with someone with chronic pain impacted significantly on partners' emotional well-being, physical health, relationships, occupation and social activities. Partners' illness representations significantly predicted their psychosocial adjustment and coping behaviours. Partners interviewed gave detailed accounts of their experiences of living with someone with chronic pain, how it impacted on their lives and how they coped.

Conclusions: This study highlights the impact of chronic pain on partners, who are often much neglected by services. Despite study limitations, an exploration of the relationship between partners' illness perceptions, coping and psychosocial functioning suggests important new ways of working with chronic pain partners. Important clinical and theoretical implications are discussed. Further work is needed however to better understand the complexities underpinning illness representations and the impact of chronic pain on partners.

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1. INTRODUCTION

1.1 General Overview

This study integrates four strands of research: psychosocial adjustment to chronic illness, coping with chronic illness, the role of illness representations in adjustment and coping, and partners' experiences of living with someone with chronic pain.

This introduction aims to present the key theoretical concepts and empirical findings in these four areas that are relevant to this study. Firstly, it provides an overview of the demography and aetiology of chronic pain, along with the implications for health providers. Then it considers the impact of chronic pain on partners, drawing upon findings from studies that have explored the impact of a range of chronic illnesses on partners. Theoretical frameworks that have been used to understand this impact on partners are also considered. In the next section, the relationship between illness representations, coping with chronic illness and the impact of illness on patients and partners is discussed. Finally the themes explored are drawn together to provide a conceptual understanding of the rationale and aims of the study. This culminates with a statement of hypotheses.

1.2 Chronic Pain

1.2.1 Demography

Chronic pain can be defined as *"pain that persists beyond normal tissue healing time, which is assumed to be three months"*, despite medical investigations and treatment, and which is benign in nature (International Association for the Study of Pain, 1986). Estimates of its prevalence in the general population have varied between 2% to 45% depending upon the specific definition of chronic pain used (Crook, Rideout and Browne, 1984; Croft, Rigby, Boswell, Schollum and Silman, 1993). Lower prevalence rates are reported in studies that have defined chronic pain as a pain persisting over a longer duration e.g. six months or more. Similarly, higher prevalence rates have been reported when studies have included less severe pain conditions. A recent study by Elliot and her colleagues (1999) of a random sample of 5306 patients, taken from 29 general practices in the Grampian region of the UK, found 50% of respondents self-reported chronic pain (equivalent

to 47% of the general population). The most common complaints reported were back pain and arthritis, which accounted for a third of all complaints. Forty-eight % of respondents reported their pain to be at the lowest grade of severity, whereas 228 (16%) reported the highest severity of pain. Twenty-eight percent of respondents also indicated high expressed need.

Studies have explored the individual's experience of chronic pain. Whilst they acknowledge the subjective nature of pain i.e. that individuals respond to pain differently and that not all patients with the same condition respond in the same way, a profile of a 'typical' chronic pain patient does emerge from these studies. This profile includes; high levels of disability, employment difficulties, impaired social and marital relationships, emotional distress, and high use of analgesic medication (Verhaak, Kerssens, Dekker, Sorbi and Bensing, 1998).

1.2.2 Aetiology

There are a number of clinical conditions in which pain predominates, including osteoarthritis, rheumatoid arthritis, low back pain, fibromyalgia, headache, heart and vascular pain, abdominal pain, spinal injury and cancer. In the UK the most prevalent chronic pain condition is back pain. Despite its frequency back pain is notoriously difficult to diagnose and possible causes often remain obscure.

Possible sources of low back pain include the intervertebral disc, nerve roots, lumbar facet joints, the paraspinal muscles, and the posterior longitudinal ligament (Cavanagh and Weinstein, 1994).

Within the workplace certain occupational activities have been associated with an increased risk of back pain such as heavy lifting, static work postures, bending and twisting and exposure to vibration. Work dissatisfaction is also a psychosocial factor associated with low back disability. There does not appear to be any relationship between height, weight, body build and low back pain, but physical fitness is associated with more rapid recovery of acute back pain episodes and a lesser risk of chronic back pain (Anderson, 1991).

1.2.3 Implications for society and health services

Chronic pain is well recognized as a common problem in today's society and is known to affect not only general health but also psychological health and social and economic well-being. The effects of chronic pain on the community are significant. It is the most frequent cause of activity limitation in people below the age of 45, the fifth most frequent for hospitalisation and the third-ranking reason for surgical procedures (Cavanagh and Weinstein, 1994). It is the most common reason why people seek medical care; individuals with chronic pain use health services up to five times more frequently than the rest of the population; and many days are lost from work (Von Korff, Dworkin, and Le Resche, 1990: Von Korff, Wagner, Dworkin and Saunders, 1991: Bowsher, Rigge and Sopp, 1991).

The financial costs of chronic pain to industry are significant. Employers, trade unions and related organizations have highlighted chronic pain as a major workplace issue and recently the TUC reported on *"the hidden workplace epidemic"* (1998), as back pain was identified as the biggest cause of health problems in the workplace. On average, each person who suffered from back pain and related conditions took 13 working days off work during the year in 1995. The Report of the Clinical Standards Advisory Group Committee on Back Pain (1994) estimated the overall cost to industry as £5 billion. It is the leading cause of sickness absence from work, with 11 million working days lost in 1995. The most recent estimate of the annual cost of back pain to the NHS in particular was £481 million, with over 12 million GP consultations, 7 million physical therapy sessions and 800,000 in-patient beds days (Elliot et al, 1999).

Within the last decade there has been significant interest in providing treatment services to help people with chronic pain manage it more effectively. This has included work rehabilitation programmes and the provision of pain management interventions much earlier in the course of pain conditions and during acute episodes (Ogden, 2001).

1.3 The impact of chronic pain on the spouse

Within the last two decades, there has been increased attention paid to the social context of the chronic pain patient, in particular the role of families (Kerns and Payne, 1996). Whilst empirical evidence is sparse, current literature focuses on two key areas of patient-family interaction: (i) mechanisms by which the family affects the chronic pain process, in relation to its development and the maintenance of pain behaviours (Jamison and Virts, 1990; Turk, Kerns and Rosenberg, 1992) and (ii) the impact of chronic pain on the family. In addition, studies have investigated factors that mediate the effects of chronic pain on the psychosocial adjustment of patients and their families. Factors highlighted include levels of social support (Subramanian, 1991), self-esteem (Druley and Townsend, 1998) the quality of the marital relationship (Turk et al, 1992), the family environment (Tota-Faucette, Gil, Williams, Keefe and Goli, 1993) and family constructs and appraisals of coping (Bush and Pargament, 1997; Snelling, 1994).

Studies that have attempted to understand the experience of living with someone with chronic pain (Mackay, 1997) and to measure the impact and effects of chronic pain on the family unit (Kerns, 1994; Roy, 1992), have found that chronic pain can affect partners on various levels: depression and marital satisfaction (Schwartz, Slater, Birchler and Atkinson, 1991), physical functioning (Flor, Turk and Scholz, 1987), social and sexual relationships (Snelling, 1994) and quality of life (Ferrel, 1995). Studies have also found a significant impact on the children of chronic pain patients, specifically illness behaviour and maladjustment (Jamison and Walker, 1993; Chun, Turner and Romano, 1993).

Although a multitude of factors will influence partners' adjustment, research has drawn attention to a number of key processes, which may be unique to their experience. In particular feelings of helplessness may predominate, and partners may feel they are unsupported. In her qualitative study of female spouses of chronic low back pain sufferers, Mackay (1997) found that spouses commonly experienced frustration because they could not do anything about their partners' pain, had difficulty looking into the future, dealt with situations one day at a time and had learned to adapt and do things differently.

Whilst acknowledging that living with someone with chronic pain may affect a partner's psychological well-being and the quality of their marital relationship, Bebbington and Delemos (1996) stress the interactive nature of the impact of chronic pain, highlighting that the patient may equally be adversely affected by a depressed, frustrated and ambivalent spouse. Research findings from both studies investigating the impact of chronic pain on families and exploring the role of families in chronic pain would therefore seem to suggest that working with the families, and in particular the partners, of chronic pain patients is a necessary requisite for improving the outcome for patients.

1.4 Living with chronic illness

1.4.1 Impact of Chronic Illness' on Partners – Research Findings.

As already shown illness does not occur within a vacuum and it impacts on more than the ill individual. Studies have highlighted the role of social support in coping with stressful life events, conceptualising adjustment to illness not just as a personal resolution, but one which is achieved through contact with significant social relationships (Feign, 1994). Such relationships are more often than not found within the family. The family, and in particular the spouse, usually serves as the first line of support, nurturance and interpretation of any illness diagnosis for the patient. In this way partners and other family members are directly confronted with the illness experience and all its demands (Lewis, 1990), which can have a huge impact on their emotional and physical well-being.

There has been extensive work on the role of family systems in a range of chronic illnesses and disabilities such as schizophrenia (Birchwood, 1983), alcohol abuse (McCrady and Hay, 1987), anorexia (Palmer, Marshall and Oppenheimer, 1984), dementia (Gilhooly, 1984; Braekhus, Okensgard, Engedal and Laake, 1998), motor neurone disease (Goldstein, Adamson, Jeffery, Down, Barby, Wilson and Leigh, 1998), breast cancer (Ben-Zur et al, 2001) renal disease (White and Grenyer, 1999) and brain damage (Moffat, 1978). The findings from these studies highlight the significant impact of living with someone with a chronic illness, particularly the spouse, in the following areas: emotional distress (e.g. anxiety, anger and

depression), physical health, social relationships, occupational roles, sexual relationships, marital satisfaction and general lifestyle changes including changing roles and responsibilities.

In his attempts to understand how families cope with living with a chronic disorder, Jim Orford (1987) suggests that chronic illnesses are indeed 'family illnesses'. He identifies themes common to all families coping with chronic disorders, which can be considered according to three broader categories:

- *the personal experience* i.e. coping with practical hardships, with the demands of treatment, with uncertainties, guilt and social restriction and with the uncertainty of how to react to difficult behaviour.
- *the family experience* i.e. balancing household tasks, and coping with the effects on family relationships e.g. the loss of reciprocity, breakdown of normal communication, deficient joint decision making, loss of sexual behaviour and disruption of normal patterns of affection and cohesion.
- *the extended family and wider community experience* e.g. gender roles.

Nichols (1987) also draws attention to the bi-phasic patterns of the experience of families dealing with physically disordered individuals. The initial phase has to do with the impact of the illness, the fright and confusion, glimpsing the long-term threats and dealing with the logistics of care. In this phase health service professionals share more of the responsibility. Later, however, during the second phase the spouse shoulders most of the burden and becomes the caregiver. It is in this phase that spouses can become isolated and are at risk of emotional and physical exhaustion. This transition of responsibility from health professionals to family according to the service view that "*the patient is doing well at home*" and is in rehabilitation, is a dangerous myth according to Nichols. Instead he suggests "*patient at home, partner now at risk*" to be a more accurate perception.

1.4.2 Understanding the impact of chronic illness on partners

A number of attempts have been made to provide a theoretical framework for understanding the impact of illness on partners. One such attempt is the illness task model (Nichols, 1987). Nichols conceptualises physical illness as a set of

tasks or hurdles to be dealt with or mastered. If the patient, partner or any other family member fails to master these tasks they will suffer adverse psychological consequences. Nichols lists the following 'tasks' that challenge the close partner of the ill person:

- *Dealing with the ill person's pain, incapacity or disfigurement.* This poses a daily conflict for a partner: to remain supportive they need to be close and empathic showing recognition of the suffering, but to remain stable and effective as a care-giver, they must not identify too much or become engulfed by the suffering.
- *Dealing with the ill person's emotional response.*
- *Dealing with the hospital environment and treatment procedures.*
- *Preserving a positive image of and positive relationship with, the ill person.*
When this task is achieved and the partnership does adapt and mutually adjust to the illness, mutual respect and the quality of the relationship can be significantly enhanced.
- *Maintaining other relationships: meeting one's own needs.* This also causes conflict for partners who may feel like they have betrayed their ill partner in preserving their own personal identity.
- *Maintaining a balanced perspective.*

Whilst the illness task model usefully highlights the huge impact on a family of dealing with the specific challenges posed by chronic illness, the illness task model overlooks the role of cognitions in this process.

An alternative model for understanding the impact of chronic illness has been suggested by the stress and coping model (Lazarus and Folkman, 1984). Unlike the illness task model, the stress and coping model places much greater emphasis on cognitions. Lazarus and Folkman propose a three-staged model of perceived stress according to the cognitive appraisals that individuals make. According to their model, a spouse facing a stressful event, such as their partner's chronic pain makes an appraisal of the threat, loss or challenge posed by the chronic pain (primary appraisal), as well as the resources available to deal with it (secondary appraisal). The spouse then responds to the perceived threat using the chosen coping strategy.

It is suggested that coping operates in a continuous cycle of appraisal and reappraisal thus perceptions of stress are seen as an ongoing transaction between the spouse and their environment. Adaptive coping is regarded as a dynamic process, responsive to a changing context. The coping strategies that a spouse may adopt are seen as either problem-focused (e.g. seeking instrumental social support) or emotion-focused (e.g. denial).

The stress and coping model is widely accepted and has been used in several studies of chronic health conditions e.g. spinal cord injury (Kennedy et al, 1999), multiple sclerosis (Schwartz, 1999) and psoriasis (Hill, 1999). However, this model has also been criticised for being too narrow in focus for giving insufficient recognition to social and interpersonal factors. In an attempt to redress this, Coyne and Smith (1991) introduce a third category of coping, 'relationship-focused', which occurs between patients and their partners as they grapple with each other's presence and emotional needs. In their study of couples coping with myocardial infarction two broad classes of relationship-focused coping are identified: active engagement and protective buffering.

An alternative model of illness impact that addresses the social context of the chronically ill person is the family systems illness model (Minuchin, 1974; Patterson and Garwick, 1994; Rolland, 1999). Here the family is conceptualised as a system, within which each member has the ability to influence each other. Changes that occur in one part of the family are compensated for by changes in another part. When illness occurs in a family member, therefore, its effects permeate the rest of the family. Illness is conceptualised according to its pattern of psychosocial demands over time. Chronic illness is viewed developmentally, involving the intertwining of three evolutionary strands: the illness, the individual and family life. The model also attends to multigenerational patterns and belief systems, including culture, gender and ethnicity.

Using family systems theory, Patterson and Garwick propose that certain factors will influence the response of partners to the chronic pain. Via circular and continuous feedback, these responses influence the adjustment and adaptation of

the individual with chronic pain, which in turn influence the partner's response. And the cycle continues. The family attempts to maintain 'homeostasis' or 'a balance of functioning' by using its capabilities (its resources and coping capacities) to meet the demands and stressors associated with the chronic illness. The meanings that the family ascribe to the demands of the illness and to its own capabilities are what influence the balance of functioning.

According to the model 'adjustment' within the family, referred to as the dynamic process that occurs when faced with acute stress, is differentiated from the process of 'adaptation', which takes place over a longer period of time and during which homeostasis is restored by the development of new resources and coping strategies (Rolland, 1999).

Whilst the family illness model draws attention to the interaction between patients and their families, and is useful for understanding the maintenance of certain illness behaviours, its model of the family as a system overshadows individual processes and fails to explain how and why an illness impacts on particular family members.

1.5 Illness Representations

1.5.1 Leventhal's Self-Regulatory Model.

A more useful framework to begin to understand the impact of illness on patients and their families, therefore, is offered by Leventhal's Self-Regulatory Model (Leventhal, Nerenz and Steele, 1984; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller and Robitaille, 1997). Unlike the other models mentioned, it provides a theoretical framework that specifically incorporates cognitions, emotional responses and coping procedures. It also acknowledges that dealing with health threats is a dynamic process, and that illness cognitions and beliefs may change over time. Furthermore whilst the model focuses on individual processes, it also acknowledges that social and cultural contexts shape both the appraisal process and the behaviours chosen for dealing with the illness situation.

Using cognitive theory, Leventhal introduces the concept of illness representations, which are defined as: *"implicit theories of illness, which give personal meaning to*

symptoms and act as a framework to guide and evaluate how a person copes with illness". Illness representations are cognitive representations based on factual information, personal experience and cultural beliefs. They are a function of an individual's semantic knowledge (e.g. the relation of symptoms to diseases; their understanding of the disease and treatment options) and specific contextual factors such as the nature of somatic changes and situations in which they occur. This semantic knowledge accumulates across the lifespan, and symptoms and contexts will vary as a function of the individual's age and social circumstances. Within this framework, therefore, the individual becomes an active processor of information about illness related events, rather than a passive object upon which illness impacts.

Based on the cognitive assumption that one's beliefs and cognitions influence one's behaviour and affect, Leventhal suggests that patients evaluate health threats by constructing their own representations or perceptions which influence their patterns of coping and their emotional responses. It is suggested that these responses occur simultaneously, referred to as the 'parallel response' process. It is suggested that illness representations contain a number of discrete attributes, which determine coping behaviours and emotional response to illness. Five attributes are identified (Lau and Hartman, 1983):

- **'identity'** i.e. ideas and beliefs about the label and symptoms of illness.
- **'time-line'** i.e. perceptions of the probable duration of illness.
- **'causal'** i.e. beliefs about the cause of illness.
- **'consequences'** i.e. beliefs about the severity and seriousness of illness and perceptions of impact on life.
- **'control/cure'** i.e. beliefs about the controllability of illness, the extent to which they or others can influence the course/outcome of illness and ideas about possible cures.

These attributes are organised and function as sets. Leventhal et al (1997) suggest that there are three types of disease model: (i) acute episodes of illness, (ii) cyclical flare-ups of illness and (iii) chronic illness. The model assumes that the pattern of

identity, cause, time-line, control and consequence attributes varies by disease (e.g. flu – coughs, stuffed nose, fever and fatigue symptoms; viral cause; 2-10 days duration; will go away by itself; disrupts daily life). A framework that enables different types and patterns of illness representation to be identified seems particularly useful, therefore, for understanding the impact of a particular condition on a particular group of individuals e.g. chronic pain partners.

1.5.2 Research Findings

Leventhal's theory of illness representations has, over the last decade, been used in studies of various chronic illnesses and conditions to investigate the role of illness beliefs and perceptions in patient adjustment and outcome e.g. chronic fatigue syndrome (Moss-Morris, Petrie and Weinman, 1996; Heijmans, 1998), rheumatoid arthritis (Pimm, 1997; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman and Rooijmans, 1998; Schaffiano, Shawaryn, and Blum, 1998), chronic obstructive pulmonary disease (Scharloo et al, 1998), multiple sclerosis (Schaffiano, Shawaryn, and Blum, 1998), Addison's disease (Heijmans, 1999) and psoriasis (Fortune, Richards, Main and Griffiths, 2000).

These studies have indicated the direct effects of illness representations on patient functioning. Heijmans (1998) found that illness representations were stronger predictors of adaptive outcome than coping scores in individuals with chronic fatigue syndrome and Addison's disease, with the exception that coping appeared to mediate the relationship between illness representations and mental health outcomes in the latter study (Heijmans, 1999). Moss-Morris, Petrie and Weinman's (1996) study of chronic fatigue syndrome found that those patients with a strong illness identity, who believed their illness was out of control, caused by stress and had very serious consequences were most disabled and psychologically impaired. Disengagement coping strategies and venting emotions were also associated with greater disability and poorer psychological well-being, while positive reinterpretation and seeking social support were positively related to psychological well-being. Overall illness perceptions explained a greater percentage of the variance in levels of disability and psychological well-being than did the coping strategies used by the patients to manage their illness.

1.5.3 The Role of Illness Representations in Pain

Within the last two decades the role of illness cognitions and beliefs in chronic pain has been increasingly researched. Studies have explored the relationship between pain cognitions and psychosocial functioning in chronic pain patients (Stroud, Thorn, Jensen and Boothby, 2000; Turner, Jensen and Romano, 2000). Findings support the predictive status of pain cognitions and representations in patient functioning and adjustment. Morley and Wilkinson's (1995) study of 84 patients with chronic pain found increased pain duration and intensity in patients believing that pain is constant, permanent and non-mysterious. Williams, Robinson and Geisser (1994) found causal beliefs were related to depression. Patients attributing the cause of their pain to themselves had significantly higher levels of depression.

Scharloo, Kaptein, Weinman, Hazes, Breedveld and Rooijmans (1999) examined 71 patients with rheumatoid arthritis in a two-year longitudinal study of the relationship between illness representations, coping strategies and outcome. They found that illness representations were associated with the number of hospital admissions and visits to outpatient clinics, levels of anxiety, depression, fatigue, functional disability and pain. Patients who believe their pain will continue (timeline) have been found to report more depressive symptoms than those who believe their pain will go away or come and go (Skevington, 1993). Beliefs about control have also been found to be associated with pain intensity (Flor and Turk, 1988; Jensen and Karoly, 1992; Jensen, Turner and Romano, 1994). Patients with low and medium pain levels who believed themselves to be disabled demonstrated significantly lower levels of activity and psychological well-being and higher levels of professional service utilization. When patients underwent treatment, which aimed to change their control beliefs and perceptions of themselves as disabled, their physical functioning improved and their depressive symptoms reduced significantly.

1.6 The Role of Illness Representations in Partners

In attempting to understand the social context of chronically ill patients, a few recent studies have used Leventhal's model as a framework for exploring illness representations within the family, in particular partner's perceptions of illness. In a cross-sectional study of patients suffering from chronic fatigue syndrome and Addison's disease and their partners, Heijmans, Ridder and Bensing.(1999)

examined the effects of dissimilarity in a couple's illness representations on coping behaviour and adaptation. Similarly, Weinman, Petrie, Sharpe and Walker's (2000) study of causal attributions in patients and spouses following first time myocardial infarction found that spousal attributions of poor health habits were associated with improvements in patients' exercise level at 6 months.

In addition to these studies, two studies have examined the relationship between partners' illness perceptions and partners' psychosocial functioning. McClenahan and Weinman (1998) explored the role of illness representations and coping in determining carer/partner distress in non-acute stroke. A significant amount of the variance of carer distress was explained by two coping strategies (venting and suppression) and the illness perception factor timeline. Those carers who perceived the illness to have a longer duration were more distressed.

Barrowclough, Lobban, Hatton and Quinn (2001) studied models of illness in carers of schizophrenic patients. They found carer's illness representations were associated with carer functioning, the patient-carer relationship and patient illness characteristics. Using a modified version of the IPQ-R, this study found carer's perceptions of the consequences of schizophrenia for both the patients and themselves, and a strong illness identity, were positively related to carer distress, depression and subjective burden. Carer's perceptions of the consequences for their relationship with the patient was also positively related to negative feelings expressed by the patient towards the carer, and negative feelings perceived by the patient from the partner. Criticism from the carer towards the patient was also inversely related to carer's control representations.

An extensive review of the literature would suggest that to date no study has investigated illness representations of chronic pain partners, particularly the relationship between partners' illness perceptions, psychosocial adjustment and coping. An increased understanding of these processes may further explain the differences between those 'chronic pain partners' who cope well and those who do not. It is hoped that this greater understanding will be useful clinically as it may suggest additional ways of helping partners to cope with supporting and living with

someone with chronic pain, which in turn may improve patient psychosocial adjustment and functioning.

1.7 Summary

A review of this area has established a number of key points. Chronic pain is a widely prevalent condition and is associated with problems with psychological adjustment and social functioning for a sizeable proportion of patients. It has been established that illness does not solely impact on the individual, but impacts on significant others, particularly partners. Adjustment to illness is therefore seen as an interpersonal process, within the dyadic relationship, and within a social context. The dynamics inherent in this process are complex. Attempts to understand the impact of illness of individuals and their partners' have been undertaken and a range of models proposed including the task illness model, the family systems illness model, the stress and coping model and the illness representations model. The advantages of using Leventhal's model to understand the impact of illness compared to other models have been highlighted. Based on Leventhal's model, studies have explored the relationship between illness representations, coping behaviours and psychosocial functioning in patients with a range of chronic illness including chronic pain. More recently, this model has also been applied to carers of patients with chronic illness. Carer's illness representations have been found to be associated with their own psychosocial functioning and that of the patient.

Research has shown that illness has significant impact on partners and therefore it is important to understand the experience of partners. Previous studies have explored the impact of chronic pain on partners, but to date no study has used the illness representations framework to understand the experiences of chronic pain partners.

This study, therefore, aims to understand more fully the experience of living with someone with chronic pain using the illness representations framework. It focuses on partners to redress the imbalance of currently available studies on illness representations, which have largely focused on the individual patient. Based on previous research it is proposed that a knowledge of illness representations in this population, together with an understanding of the nature of the interaction between

illness representations, coping and adjustment to chronic pain will enable clinicians to identify partners who may be at risk of adjustment difficulties. Once identified, it is proposed that increased knowledge of these processes will enable clinicians to devise effective therapeutic interventions, which will further facilitate the adjustment process in both chronic pain patients and their partners.

1.8 Research Questions

- *What is the psychosocial functioning and adjustment of partners living with someone with chronic pain?*
- *What are partners' representations of chronic pain?*
- *What are partners' experiences of living with someone with chronic pain?*
- *What strategies do partners use to cope with living with someone with chronic pain?*
- *Do partners' representations of chronic pain predict their psychosocial functioning and adjustment to living with someone with chronic pain?*
- *Do partners' representations of chronic pain predict the strategies that they use to cope with living with someone with chronic pain?*

1.9 Hypotheses

Hypothesis 1:

The psychosocial functioning and adjustment of partners to living with someone with chronic pain will be similar to that of partners living with other chronic illnesses.

Hypothesis 2:

Partners illness representations and coping behaviours will account for more of the variance in psychosocial functioning and adjustment than demographic and disease variables.

Hypothesis 3:

Partners illness representations will account for more of the variance in coping behaviours than demographic and disease variables.

2. METHOD

2.1 Participants

The participants were partners of chronic pain patients. Partner was defined as a spouse or co-habitee. The chronic pain patients were recruited from the client register of the Chronic Pain Management Team (CPMT) at Rayner's Hedge, Aylesbury, a community physical disability and rehabilitation service. Patients were excluded according to the following criteria:

- i) Patients who had been referred for pain management but whose primary diagnosis was not chronic pain e.g. chronic fatigue syndrome.
- ii) Patients who were waiting for an assessment by the CPMT, and were thus 'unknown' to the team.
- iii) Patients who currently did not have a partner.
- iv) Patients who had been bereaved within the last 12 months.
- v) Patients who were identified by the CPMT as being inappropriate participants e.g. patients with severe mental health difficulties, or where partners did not speak English.

2.2 Design

The study was a cross-sectional survey design, using both quantitative and qualitative data. The independent variables were the illness perceptions of chronic pain partners, and partners coping' behaviours (hypothesis 2). The dependent variables were partners' coping (hypothesis 3) and psychosocial adjustment to chronic pain in five main areas (emotional well-being, physical health, relationships, occupation and social activities). Data was obtained using a combination of questionnaires and semi-structured interviews following Leventhal's original design and subsequent recommendations (Weinman, Petrie and Moss-Morris, 1996).

2.3 Measures

2.3.1 Demographic and Disease question sheet.

An introductory question sheet was devised to obtain the following demographic and disease data: age, gender, employment status, occupation, years of education, length of relationship, pain duration and pain severity.

2.3.2 The General Health Questionnaire (GHQ-28) (Goldberg and Williams, 1988). The General Health Questionnaire is a self-administered screening instrument designed to detect non-psychotic psychiatric disorder. The GHQ-28 provides four scores measuring somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. Items are scored using a 0-3 Likert scale. In this study only the 7 items of the somatic symptoms scale were used. The GHQ-28 has been shown to have a high degree of validity and good levels of internal consistency and test-retest reliability (Goldberg and Hillier, 1979).

2.3.3 The Short-Form-36 Health Survey (SF-36) (Ware and Sherbourne, 1992). The 36-item short form of the Medical Outcomes Study questionnaire (SF-36) was designed as a generic indicator of health status for use in population surveys. It includes multi-item scales to measure eight dimensions of health status. Only two scales were used in this study: all 10 items from the physical functioning scale (scored using a 1-3 Likert scale) and Item 1 of the general health perceptions scale (which is scored using a 1-5 Likert scale). Scores from the physical functioning scale are then linearly transformed to a 0-100 scale. Several studies have found the SF-36 to have excellent psychometric properties. Cronbach Alpha co-efficients reported for the physical functioning and general perceptions scales all exceed 0.80 (Ware and Sherbourne, 1992). Test-retest correlations also exceed 0.80. (Kantz et al, 1992; McHorney et al, 1994; Brazier et al, 1992; Jenkinson et al, 1994).

2.3.4 The Revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick, 2001). The Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris and Horne, 1996) was developed to provide a quantitative assessment of the five components of illness representations – identity, consequences, timeline, control/cure and cause in Leventhal's Self-Regulatory Model (Leventhal, Nerenz and Steele, 1984; Leventhal et al, 1997). It has been used in studies of patients with a wide range of conditions including heart disease, rheumatoid arthritis, cancer, psoriasis, chronic obstructive pulmonary disease, chronic fatigue syndrome and Addison's disease. It has also been adapted for spouses and carers of people with major health problems

(Heijmans, de Ridder and Bensing, 1999; McClenahan and Weinman, 1998; Weinman, Petrie, Sharpe and Walker, 2000).

In addition to the original IPQ dimensions, the IPQ-R includes three further subscales, assessing cyclical timeline perceptions, illness coherence and emotional representations. The control/cure subscale of the IPQ has also been subdivided in the IPQ-R, with separate scales for personal control and treatment control.

Although relatively new, the IPQ-R has been found to have both good internal reliability and short (3 week) and long term (6 months) retest reliability (Moss-Morris et al, 2001). Studies also demonstrate sound discriminant, known group and predictive validity (Moss-Morris et al, 2001).

For the purpose of this study permission was obtained from the authors to adapt the IPQ-R for chronic pain partners by slightly changing the wording of statements e.g. 'your illness' became 'their pain'. The first part of the modified IPQ-R lists 14 symptoms. Respondents indicate which of the symptoms their partners experience and which of the symptoms are attributed by the partner to the chronic pain. The second part of the IPQ-R consists of 38 statements which individuals' rate using a five-point Likert scale: strongly disagree, disagree, neither agree nor disagree, agree, strongly agree. This provides scores for the timeline, timeline cyclical, consequences, personal control, treatment control, illness coherence and emotional representation dimensions. The final part provides a list of 18 possible causes for their partners' chronic pain, which respondents' rate using the same five-point scale. Possible causes can be grouped into four categories of attributions: psychological, risk factor, immune and accident/chance (Moss-Morris et al, 2001).

2.3.5 The Psychological Adjustment to Illness Scale – Self report (PAIS-SR) (Derogatis and Derogatis, 1990). This questionnaire assesses psychosocial adjustment to the sequelae of illness. It provides a measure of overall adjustment in seven domains: health care orientations, vocational environment, domestic environment, social environment, sexual relationships, extended family relationships and psychological distress. For the purpose of this study, the health care orientation domain was omitted as it was felt to be irrelevant to the aims of the study and inappropriate for a British sample. Permission was obtained from the

authors to adapt the questionnaire for chronic pain partners by slightly changing the wording, as recommended in the manual guidelines.

For each of the 38 statements, respondents were asked to rate the effect of their partner's pain on their lives within the six domain areas. Each response was scored on a 0-3 scale, with higher scores indicating poorer adjustment. Total scores are obtained for each domain and overall. Domain raw scores are then converted to standardized area T-scores (mean = 50, standard deviation = 10) using published norms. As there are currently no chronic pain norms, norms for cancer (mixed diagnoses) were used in this study. The PAIS-SR has been used extensively in research in a range of illness populations including chronic pain and has acceptable reliability and validity (Derogatis and Derogatis, 1990).

2.3.6 The COPE (Carver, Scheier and Weintraub, 1989).

The COPE is a multidimensional coping inventory incorporating 13 conceptually distinct scales that have been found to either facilitate or impede active coping in different contexts. The 13 coping scales are: active coping, planning, seeking instrumental social support, seeking emotional social support, suppression of competing activities, turning to religion, positive reinterpretation and growth, restraint coping, acceptance, focusing on and venting of emotions, denial, mental disengagement and behavioural disengagement. Since its development, two further scales have been added – alcohol/drugs and humour – which are regarded as more exploratory. The inventory is self-administered and has advantages over other coping measures in that it can be used to assess situational or dispositional coping.

For the purpose of this study the introductory wording was adapted slightly to be specific to partners coping with chronic pain, following guidelines for situational versions. Carver et al (1989) report the internal consistency of the COPE to be acceptable and reasonably stable test-retest reliabilities (0.42-0.89).

2.3.7 Semi-structured interview

The semi-structured interview consisted of a combination of closed and open-ended questions. The first section elicited basic demographic data: age, gender,

occupation, educational history, length of relationship, duration of pain and pain severity. The second section was designed to reflect the conceptual dimensions of the illness representation model, thus obtaining further detailed information about these dimensions. A section then focused specifically on the partner's relationship with the patient. The final section focused on coping and on partners' experiences of services.

2.4 Ethical Approval

Full ethical approval for this research was received from the Aylesbury Vale Local Research Ethics Committee (*Appendix I*). As this study aimed to explore partners' experiences of living with someone with chronic pain, the possibility that some participants might become distressed during the interviews was considered. In discussion with the chronic pain management team it was agreed that if any partners became particularly distressed during an interview, the interview would be stopped and partners would be advised to consult their G.P.

2.5 Procedure

Following approval from the local research ethics committee, the questionnaires and interviews were piloted. Recruitment for the pilot study took the form of approaching a current treatment group for volunteers. Five patients (out of a group of nine) volunteered their partners for the pilot study. The researcher contacted the partners and, once participation had been agreed, questionnaires were sent out. Partners were followed up one week later with a telephone call from the researcher, who recorded any difficulties the partners' had completing the questionnaires and the time it had taken them to complete the pack. Two of the pilot participants also volunteered to take part in the pilot interviews. Both interviews followed a semi-structured interview schedule, and were recorded on audiotape.

Before questionnaire packs were sent out, the researcher liaised with the CPMT at Rayner's Hedge to determine the suitability of the participants. Participants were excluded according to the aforementioned criteria. A letter was also sent to the patients' G.P's giving details of the study and requesting G.P's to contact the researcher if they had any concerns about their patient and their patient's partner being invited to participate (*Appendix II*). Questionnaire packs were then sent out

to 146 patients selected from the CPMT client register. The packs consisted of an introductory letter (giving details of the study and contact details for anyone wishing to have any further information), a patient consent form (to ensure patients were happy for their partners to participate), a partner consent form, partner questionnaires and a pre-paid reply envelope (*Appendix III*). At the bottom of the consent forms space was provided for partners to give their contact details if they wished to be interviewed. Questionnaires were sent out between December 2000 and January 2001. A reminder letter was also sent out in February 2001 (*Appendix IV*).

Interviewees were selected randomly from the list of 29 partners who had given their contact details. In total 10 partners were interviewed. Interviews took place at Rayner's Hedge or at the interviewee's home between January and March 2001. A semi-structured interview schedule was followed (*Appendix V*). Interview length ranged from 55 to 85 minutes. At the beginning of each interview, interviewee's were given the opportunity to discuss the study and ask any questions. They were advised that they could stop at any time and that they did not have to answer any questions they were not comfortable with. They were reminded that the information given was confidential and that it would be anonymised in the data analysis and that all tape recordings would be wiped clean after interview transcription. The independence of the study was reiterated and they were reminded that the information given would in no way affect their partner's treatment.

3. RESULTS

This section has three main components:

- i) Presentation of the descriptive data relating to the participants and their partners.
- ii) The main statistical analyses including: the rationale for the statistical tests used and presentation of the main findings in relation to the hypotheses.
- iii) Qualitative data, summarising the key themes extrapolated from the interview data.

3.1 Descriptive Data

3.1.1 Response Rate

One hundred and forty-six patients with chronic pain were sent questionnaires. Sixty-five questionnaires were returned (44.5%). Thirty (46%) of returned questionnaires were incomplete. The two main reasons given for not completing the questionnaires were 'having no partner' and 'partner having no time to participate'. Thirty-five (24% of the total sent) questionnaires were returned completed. Of the 35 partners who completed the questionnaires, 29 (82.9%) volunteered to be interviewed.

From comments made by participants to the researcher in response to the follow-up letters, it is possible that the response rate was seriously affected by two postal strikes that occurred around the time of questionnaire distribution. It was discovered that several patients had not received the original questionnaire packs. Furthermore completed questionnaires that had been posted back to the researcher were not received. By the time this was discovered, however, the researcher was unable to continue trying to recruit more participants.

3.1.2 Age and Gender

The age of partners ranged from 30 to 80 years. The mean age was 48.7 years (standard deviation = 12.5). Partners were almost equally distributed according to gender, with 16 (45.7%) partners being female, and 19 (54.3%) male.

3.1.3 Current employment and Socio-economic status

Partners' current employment status is presented in Table 1. Over half (54.3%) of the chronic pain partners were in full time employment, whilst a fifth had retired from work. Five (14.3%) partners were no longer working, as they were full-time carers for their spouses.

Table 1: Partners' current employment.

Current employment situation	Frequency	Percentage (%)
Full-time	19	54.3
Part-time	3	8.6
Unemployed – seeking work	0	0.0
Unemployed – not seeking work	5	14.3
Full-time education	0	0.0
Retired from work	7	20.0
Other	1	2.9
TOTAL	35	100.0

Details of participants' and their partners' occupations were also obtained to establish the combined socio-economic status of each household, in accordance with the new National Statistics Socio-economic Classification guidelines (Rose and O'Reilly, 1998; Rose and Pevalin, 2001). Table 2 presents the combined socio-economic class (SEC) of the chronic pain patients and their partners. The socio-economic status of participants is reasonably well distributed across the nine SEC groups, with perhaps a slight skewing towards the SEC groups I. and II. (37.1%). The 'not classifiable' category is used where insufficient information has been provided to make an accurate classification.

Table 2: Socio-economic status

SEC		Frequency	Percentage (%)
I	Higher managerial and professional	7	20.0
II	Lower managerial and professional	6	17.1
III	Intermediate	4	11.4
IV	Small employers and own account workers	1	2.9
V	Supervisors / craft related	4	11.4
VI	Semi-routine occupations	4	11.4
VII	Routine occupations	1	2.9
VIII	Never worked / Long term unemployed	3	8.6
IX	Not classifiable	5	14.3
	TOTAL	35	100.0

3.1.4 Educational years

Partners were also asked to indicate the number of years they had spent in full-time education. This information is presented in Table 3. Over half the partners (51.4%) had completed secondary education, and nearly a third (31.4%) had completed tertiary education. Four (11.4%) partners had been educated at a postgraduate level.

Table 3: Educational years

Educational years	Frequency	Percentage (%)
0-7 (e.g. primary)	0	0.0
8-12 (e.g. secondary)	18	51.4
13-14 (e.g. tertiary)	11	31.4
15-17 (e.g. graduate)	2	5.7
18 + (e.g. postgraduate)	4	11.4
TOTAL	35	100.0

3.1.5 Relationship years

The length of partner’s relationships with the chronic pain patients ranged from 4 to 56 years. The mean length of relationship was 22.3 years (standard deviation = 14.1). Table 4 presents the length of relationships when grouped into 10-year periods. Nearly three-quarters (74.3%) of participants’ relationships fell within the 0-29 year range, but over a quarter (n = 9, 25.7%) of participants had been in relationships with their partners for 30 years or more.

Table 4: Length of relationship

Relationship length (years)	Frequency	Percentage (%)
0-9	8	22.85
10-19	8	22.85
20-29	10	28.6
30-39	4	11.4
40-49	3	8.6
50-59	2	5.7
TOTAL	35	100.0

3.1.6 Duration and severity of pain

The number of years that participants’ reported their partners being in chronic pain ranged form 2 to 22 years. The mean duration of pain reported was 8.4 years (standard deviation = 4.7). Participants were also asked to indicate how bad their partner’s pain had been over the past two weeks using a 0-100 visual analogue scale (0 = *no pain*, 100 = *worst pain imaginable*). Participants reported a severity of

pain ranging from 25 to 100. The average pain reported was 69.7 (standard deviation = 18.9). Table 5 presents reported severity of pain according to quartiles. Nearly a half (42.9%) of participants reported their partners to have recently suffered pain falling into the highest quartile.

Table 5: Reported severity of pain

Severity of pain (0-100)	Frequency	Percentage (%)
0-25	1	2.9
26-50	6	17.1
51-75	13	37.1
76-100	15	42.9
TOTAL	35	100.0

3.1.7 Partners’ representations of chronic pain.

The participants' chronic pain representations, as measured by the IPQ-R, are presented in Table 6. In addition to the mean and standard deviation, mean scores according to the 1-5 scale are given. The latter was obtained by dividing the means for each subscale with the number of items in each scale e.g. mean timeline = 24.9, divided by the number of items in timeline scale = 6, gives mean (1-5 scale) = 4.2.

Table 6: Mean and standard deviations for chronic pain partners on the individual subscales of the adapted IPQ-R.

IPQ-R ¹ subscale	Mean	Standard Deviation	Mean (1-5 scale)
Identity	8.0	2.4	N/A
Timeline	24.9	3.8	4.2
Consequences	26.1	2.6	4.3
Personal Control	18.1	4.2	3.0
Treatment Control	13.7	3.6	2.7
Illness Coherence	12.7	5.5	2.5
Timeline Cyclical	13.3	4.2	3.3
Emotional Representations	23.6	4.7	3.9
Cause			
<i>Psychological</i>	16.3	5.6	2.7
<i>Risk factors</i>	15.5	5.3	2.2
<i>Immunity attributions</i>	6.5	2.7	2.2
<i>Accident / chance</i>	6.3	2.2	3.2

¹IPQ-R = Revised Illness Perceptions Questionnaire.

Using the mean (1-5 scale) scores, it can be seen that the participants' as a whole perceived the consequences of chronic pain for their partners as severe (mean = 4.3), perceived the nature of their partner's condition to be chronic/long-term (mean

= 4.2), and perceived an emotional impact on their partners because of their chronic pain (mean =3.9). There was a moderate degree of agreement that their partner's pain was cyclical and unpredictable (mean = 3.3), and that their partners had some personal control over their condition (mean =3.0). There was some slight disagreement that their partner's condition could be controlled or cured by treatment (mean = 2.7). On the whole participants reported understanding their partner's condition rather than being puzzled by it (mean = 2.5). Table 6 also shows that chronic pain partners tended to make psychological and chance attributions of the pain.

3.1.8 Partners' coping behaviours.

The participants coping behaviours, as measured by the COPE, are presented in Table 7. The coping behaviours that participants reported using most frequently to help them to cope with their partners' chronic pain were acceptance, active coping, positive reinterpretation and growth and planning. The least used coping strategies reported were alcohol and drugs, behavioural disengagement, religion and humour.

Table 7: Coping behaviours of chronic pain partners.

COPE subscale	Mean	Standard Deviation
Active coping	11.3	3.2
Planning	10.5	2.9
Seeking instrumental social support	7.6	3.3
Seeking emotional social support	7.0	3.4
Suppression of competing activities	9.3	2.4
Turning to religion	6.9	4.6
Positive reinterpretation and growth	10.8	3.1
Restraint coping	8.9	3.5
Acceptance	12.5	3.5
Focusing on and venting of emotions	8.1	2.7
Denial	5.7	2.7
Mental disengagement	8.1	3.1
Behavioural disengagement	5.8	2.2
Alcohol / drugs	5.1	2.3
Humour	6.1	3.0

3.1.9 Partner's Psychological Adjustment to Chronic Pain.

Partner's psychological adjustment to chronic pain, as measured by the PAIS-SR, is presented in Table 8. In addition to mean and standard deviation, mean scores

using a 0-3 scale are given. Generally participants reported adjusting well psychologically to the effects of their partners' chronic pain. Areas where adjustment is poorer are psychological distress, sexual relationships and social activities.

Table 8: Psychological adjustment of chronic pain partners.

PAIS-SR ¹ subscale	Mean	Standard deviation	Mean (0-3 scale)
Vocational environment	4.8	3.9	0.81
Domestic environment	6.0	4.7	0.75
Sexual relationships	6.5	4.9	1.09
Family relationships	3.1	3.1	0.63
Social activities	6.5	6.0	1.08
Psychological distress	8.1	4.3	1.17
TOTAL	34.7	21.2	N/A

¹PAIS-SR = Psychological Adjustment to Illness Scale – Self-Report.

3.2 Quantitative Data Analysis

The study hypothesised that the psychosocial functioning and adjustment of partners to living with someone with chronic pain would be similar to that of partners living with other chronic illnesses. Partners' psychosocial functioning and adjustment was measured in five domains: emotional well-being, physical health, relationships, occupation and social activities. Comparative analyses with existing normative data were used to explore this hypothesis. Where possible One-Sample t-tests were also used to test for significant differences from the normative group.

The study also hypothesised that partners' illness representations would be predictive of psychosocial adjustment and coping behaviours. Stepwise regression analyses were used to explore these hypotheses. The data was assessed to ensure that it met the assumptions of linear regression and One Sample Kolmogorov-Smirnoff tests were used to test the normality of the standardised residual deviations from the regression analyses. None of these tests showed any concern about normality. For the models of interest with the IPQ-R and COPE variables in Hypothesis 2, all p values exceeded 0.4, and all but one p value exceeded 0.8. For the models of interest with the IPQ-R variables in Hypothesis 3, all p values exceeded 0.15.

3.2.1 Hypothesis 1:

The psychosocial functioning and adjustment of partners to living with someone with chronic pain will be similar to that of partners living with other chronic illnesses.

Partners' emotional well-being

Partners' emotional well-being was measured using the emotional distress subscale of the PAIS-SR and the somatic symptoms subscale of the GHQ-28 (SS/GHQ-28).

On the SS/GHQ-28 partners were asked to indicate whether they had recently experienced any of the seven symptoms listed according to a four point scale where 0 = not at all, 1 = no more than usual, 2 = rather more than usual and 3 = much more than usual. A high score therefore indicates poorer health. Scores for each item are summed to give a total score (maximum score = 21). The mean score obtained was 7.8 (standard deviation = 5.0). 48.6% of the partner's reported symptoms at the 'no more than usual' level. In contrast 51.4% of partners reported experiencing symptoms 'rather more' or 'much more' than usual. These scores could not be compared with other groups, as normative data only exists for total scores of the GHQ-28.

On the psychological distress subscale of the PAIS-SR the mean score obtained was 8.1. When converted to standardised area T-scores, the score obtained was 59. A One Sample T-test revealed that the chronic pain partners had significantly higher scores i.e. levels of psychological distress than mixed cancer patients ($t = 5.48$, $df = 34$, $p < 0.0005$) (Derogatis and Derogatis, 1990). Chronic pain partners also had significantly higher scores than partners of breast cancer patients ($t = 5.12$, $df = 34$, $p < 0.0005$) (Holdaway, 2000).

Partners' physical health

The physical health of chronic pain partners was measured using the 10-item physical functioning scale of the SF-36. Raw scores ranging from 10-30 were transformed to a 0-100 scale, with the lower score indicating poorer physical health. The mean score obtained was 70.4 (standard deviation = 33.3). This can be compared to a mean of 92.5 (standard deviation = 13.4) for adults of working age (Jenkinson, Coulter and Wright, 1993).

Comparative analysis of this data using a One Sample T-Test revealed that the score of 92.5 was significantly higher than 70.4, indicating poorer physical functioning in chronic pain partners than normal working adults ($t = -3.92$, $df = 34$, $p < 0.0005$).

In addition partners were asked to indicate the state of their health generally according to a five point scale where 1 = excellent, 2 = very good, 3 = good, 4 = fair and 5 = poor. The mean general health score was 2.9 (standard deviation = 1.2). Table 9 shows that 40% of chronic pain partners reported their general health to be very good or excellent and 31.4% reported good health. Over a quarter (28.6%) of participants reported their general health as fair or poor.

Table 9: Partners' general health.

General health rating	Frequency	Percentage (%)
Excellent	4	11.4
Very good	10	28.6
Good	11	31.4
Fair	5	14.3
Poor	5	14.3
TOTAL	35	100.0

Partners' relationships

In order to obtain a broad picture of the impact of chronic pain on partners' relationships, three domain scores of the PAIS-SR were used: domestic environment, sexual relationships and extended family relationships. Table 10 presents the means and standard deviations obtained from each domain, along with the standardised area T-score conversion.

Table 10: Partners' relationships.

Domain	Mean	Standard deviation	T-scores
Domestic environment	6.0	4.7	53
Sexual relationships	6.5	4.9	57
Family relationships	3.1	3.1	61

On the domestic environment subscale of the PAIS-SR the mean score obtained was 6.0. When converted to standardised area T-scores, the score obtained was 53. A One Sample T-test revealed that chronic pain partners did not differ significantly in the degree of impact that their partner's pain had on their domestic environment from mixed cancer patients ($t = 1.35$, $df = 34$, NS)(Derogatis and Derogatis, 1990). When compared to breast cancer partners, however, a significant difference was found between the two groups, with chronic pain partners indicating poorer adjustment than breast cancer partners in their domestic environment ($t = 5.02$, $df = 34$, $p < 0.0005$) (Holdaway, 2000).

On the sexual relationships subscale of the PAIS-SR the mean score obtained was 6.5, giving a standardised T-Score of 57. Comparative analyses revealed chronic pain partners showed significantly poorer adjustment in their sexual relationships than mixed cancer patients ($t = 4.02$, $df = 34$, $p < 0.0005$), and breast cancer partners ($t = 4.42$, $df = 34$, $p < 0.0005$).

On the extended family relationships subscale of the PAIS-SR the mean score obtained was 3.1. This gave a standardised T score of 61. Using a One Sample T-test, comparative analyses revealed chronic pain partners showed significantly poorer adjustment in their family relationships than mixed cancer patients ($t = 6.20$, $df = 34$, $p < 0.0005$) and breast cancer partners ($t = 6.48$, $df = 34$, $p < 0.0005$).

Partners' occupation

The impact of living with somebody with chronic pain on partner's occupation was measured using the vocational environment subscale of the PAIS-SR. The mean and standard deviation obtained were 4.8 and 3.9 respectively. The standardised T-score obtained was 57. Analyses using One Sample T-Tests indicated significantly poorer adjustment for chronic pain partners in their vocational life compared to mixed cancer patients ($t = 6.98$, $df = 34$, $p < 0.0005$), and partners of breast cancer patients ($t = 2.21$, $df = 34$, $p = 0.034$).

Partners' social activities

The impact of living with someone with chronic pain on partner's social activities was measured using the social environment subscale of the PAIS-SR. The mean

and standard deviation obtained were 6.5 and 6.0 respectively, which gave a standardised T-score of 51. A One Sample T-test showed no difference between chronic pain partners and mixed cancer patients in the impact of the conditions on their social environment ($t = 0.6$, $df = 34$, $p = 0.55$). In contrast, chronic pain partners showed poorer adjustment in their social environment than breast cancer partners ($t = 5.40$, $df = 34$, $p < 0.0005$).

Summary - Hypothesis 1:

- Evidence was found in part support of hypothesis 1. On the whole the psychosocial adjustment and functioning of chronic pain partners was found to be poorer than that of breast cancer partners and cancer patients themselves.
- Chronic pain partners were found to have higher levels of psychological distress than cancer patients and partners of breast cancer patients.
- The physical functioning of chronic pain partners was found to be worse than normal working adults.
- Chronic pain partners showed poorer adjustment in their domestic environment and social relationships than partners of breast cancer patients, but not cancer patients.
- Chronic pain partners showed poorer adjustment in their sexual relationships, family relationships and vocational life than cancer patients and partners of breast cancer patients.

3.2.2 Hypothesis 2:

Partners' illness representations and coping behaviours will account for more of the variance in psychosocial adjustment than demographic and disease variables.

Stepwise multiple regression analyses were carried out to explore hypothesis two. Table 11 presents the results of these analyses. As can be seen from Table 11, even when entered collectively into the regression analysis, demographic and disease variables failed to significantly predict psychosocial adjustment. In comparison, all but one of the illness representation and coping multiple regression equations identified significant predictors. As low scores on the PAIS-SR indicate better psychological adjustment, these equations showed that illness

representations and coping behaviours were negatively related to psychological adjustment i.e. the stronger the illness perception/coping behaviour the greater the impact in each area of psychosocial functioning. This was true for all equations except the relationship between perceived treatment control and the impact on family relationships. In this case the more partners perceived the pain to be controllable by treatment, the less the pain impacted on their family relationships.

Table 11: Multiple regression analyses testing Hypothesis 2 – predictors of psychosocial adjustment.

Outcome Measure (PAIS-SR)	Results of regression for demographic and disease variables ¹			Results of regression for IPQ-R and COPE variables (stepwise) ²			
	% Variance explained	F	p	Predictive variables (& beta values)	% Variance explained	F	p
Work	10.2	0.7	0.66	IPQCons (0.47) IPQTcyc (0.33)	39.1	10.3	< 0.0005**
Domestic activities	5.6	0.3	0.88	COPEBD (0.56) IPQSympt (0.40)	42.4	11.8	<0.0005**
Sexual relationships	6.0	0.4	0.86	IPQCons (0.47)	22.1	9.4	0.004**
Family relationships	12.4	0.8	0.55	IPQSympt (0.42) IPQTreat (-0.38)	32.1	7.6	0.002**
Social environment	8.4	0.5	0.75	None entered	-	-	-
Psychological distress	5.7	0.4	0.88	IPQSympt (0.51) COPEBD (0.43)	39.9	10.6	< 0.0005**
TOTAL	10.4	0.7	0.65	COPEBD (0.56) IPQSympt (0.47)	48.3	14.9	< 0.0005**

¹ Demographic and disease variables used were age, gender, relationship years, pain duration and pain severity.

² Independent variables used were:

- (a) IPQ-R - Consequences, Timeline, Timeline cyclical, Personal control, Treatment control, Illness coherence, Emotional representations and Identity (Symptoms), and Cause.
- (b) COPE - Active Coping, Planning, Seeking Instrumental social support, Seeking emotional social support, Suppression of competing activities, Turning to religion, Positive reinterpretation and growth, Restraint coping, Acceptance, Focusing on and venting of emotions, Denial, Mental disengagement, Behavioural disengagement, Alcohol/drugs and Humour.

The results of these analyses show:

- Partners' perceptions about the consequences of chronic pain for patients and it's unpredictability as a condition predicted the level of impact living with

someone with chronic pain had on partners' vocational environment, explaining 39.1% of the variance.

- Partners' perceptions about the identity of the patient's condition and their level of behavioural disengagement also predicted the impact that living with someone with chronic pain had on partners' domestic environment, explaining 42.4% of the variance.
- Partners' perceptions about the consequences of chronic pain for patients predicted the impact that living with someone with chronic pain had on partners' sexual relationships, explaining 22.1% of the variance.
- Partners' perceptions about the identity of the patient's condition and the controllability/curability of the condition via treatment predicted the impact of living with someone with chronic pain on partners' family relationships, explaining 32.1% of the variance.
- Partners' chronic pain perceptions and coping behaviours did not predict any impact on partners' social activities.
- Partners' perceptions about the identity of the patient's condition and their level of behavioural disengagement predicted partners' psychological distress and overall psychological adjustment, explaining 39.9% and 48.3% of the variance, respectively.

Summary – Hypothesis 2:

- Evidence was found in support of hypothesis 2.
- None of the demographic and disease variables significantly predicted chronic pain partners' psychosocial adjustment.
- In comparison partners' illness representations and coping behaviours significantly predicted psychological adjustment to chronic pain in partners' vocational environment, domestic environment, sexual relationships, family relationships and levels of psychological distress but not partners' social environment.

3.2.3 Hypothesis 3:

Partners' illness representations will account for more of the variance in coping behaviours than demographic and disease variables.

Stepwise regression analyses were carried out to explore hypothesis three. Table 12 presents the results of these analyses.

Table 12 shows that none of the demographic and disease variables significantly predicted the coping behaviours of chronic pain partners. In comparison over half of the multiple regression equations, using partners' illness representations as independent variables, identified significant predictors. These equations showed that illness representations were largely positively related to coping behaviours i.e. the stronger the illness perception the more frequent the coping response. An exception to this was an inverse correlation between perceptions of personal control and turning to religion i.e. the more partners perceived the pain to be controllable by the patient the less likely they used their religious beliefs to help them to cope. Causal beliefs were also found to be a negative predictor of denial, as were perceptions of controllability by treatment of behavioural disengagement.

Table 12: Multiple regression analyses testing Hypothesis 3 – predictors of coping behaviours.

Outcome Measure (COPE)	Results of regression for demographic and disease variables ¹			Results of regression for IPQ-R variables (stepwise) ²			
	% Variance explained	F	p	Predictive variables (& beta values)	% Variance explained	F	p
Active coping	9.7	0.6	0.68	None entered	-	-	-
Planning	16.2	1.1	0.37	IPQCons (0.42)	17.5	7.0	0.012*
Seeking instrumental social support	8.0	0.5	0.77	IPQPc (0.43)	18.6	7.6	0.01**
Seeking emotional social support	21.2	1.6	0.20	IPQTreat (0.56)	31.2	14.9	< 0.0005**
Suppression competing activities	3.7	0.2	0.95	IPQCons (0.44)	19.3	7.9	0.008**
Turning to religion	13.0	0.9	0.52	IPQPc (-0.49)	23.7	10.2	0.003**
Positive reinterpretation & growth	16.6	1.2	0.36	None entered	-	-	-
Restraint coping	3.0	0.2	0.97	None entered	-	-	-
Acceptance	25.3	2.0	0.12	None entered	-	-	-
Focusing on & venting emotions	6.5	0.4	0.84	IPQEmot (0.41)	17.1	6.8	0.013*
Denial	16.1	1.1	0.38	IPQTcyc (0.42) IPQCause (-0.38)	28.6	6.4	0.005**
Mental disengagement	25.4	2.0	0.11	IPQTcyc (0.48)	22.5	9.6	0.004**
Behavioural disengagement	15.6	1.1	0.39	IPQTreat (-0.37) IPQTcyc (0.35)	26.4	5.7	0.007**
Alcohol / Drugs	14.5	1.0	0.44	None entered	-	-	-
Humour	19.8	1.4	0.24	None entered	-	-	-

¹ Demographic and disease variables used were age, gender, relationship years, and pain duration and severity.

² IPQ-R variables used were: Consequences, Timeline, Timeline cyclical, Personal control, Treatment control, Illness coherence, Emotional representations and Identity (Symptoms), and Cause.

The results of these latter analyses show:

- Partner's chronic pain perceptions do not predict the following coping strategies in chronic pain partners: active coping, positive re-interpretation and growth, restraint coping, acceptance, alcohol / drug use or use of humour.
- Partners' perceptions about the consequences of chronic pain for patients predicted partners' use of planning and suppression of competing activities as coping strategies, explaining 17.5% and 19.3% of the variance respectively.
- Partners' beliefs about the patients' personal ability to control their pain predicted whether partners sought instrumental social support or turned to religion in order to cope with living with someone with chronic pain, explaining 18.6% and 23.7% of the variance respectively.
- Partners' beliefs about the controllability/curability of the pain via treatment predicted partners' seeking emotional support (31.2% of the variance explained).
- Partners' emotional representations predicted partners' use of focusing on and venting of emotions, explaining 17.1% of the variance.
- Partners' perceptions of the condition as unpredictable and cyclical predicted their use of mental disengagement as a coping strategy, explaining 22.5% of the variance.
- Partners' causal beliefs and perceptions of the condition as unpredictable predicted their use of denial as a coping strategy, explaining 28.6% of the variance.
- Partners' perceptions of the condition as unpredictable and their beliefs about the controllability/curability of the condition through treatment predicted their use of behavioural disengagement as a coping strategy, explaining 26.4% of the variance.

Summary – Hypothesis 3:

- Evidence was found in support of hypothesis 3.
- Demographic and disease variables failed to significantly predict chronic pain partners' coping behaviours.
- Partner's illness representations significantly predicted the use of the following coping strategies by chronic pain partners: planning, seeking instrumental

support, seeking emotional support, suppression of competing activities, turning to religion, focusing on and venting of emotions, denial, mental disengagement and behavioural disengagement, but not active coping, positive reinterpretation and growth, restraint coping, acceptance, alcohol and drug use, or the use of humour.

3.3 Qualitative Data

This section summarises information obtained from the interviews. It is believed that this qualitative information will help facilitate interpretation of the quantitative data and develop a fuller understanding of the processes involved in living with someone with chronic pain. The interviews were transcribed and analysed in stages according to the preliminary stages of a grounded theory approach (Pidgeon and Henwood, 1996). Firstly a transcript was read and coded on a line-by-line basis. An indexing system was constructed by assigning each code to its own index card and the specific transcript or phrase relating to that code copied onto it (*Appendix VI*). These existing codes were then used to code each additional transcript, along with any new codes created. The number of new codes created decreased with each additional transcript, as the data became 'saturated'. No new codes were created after the seventh transcript was coded. Codes were therefore generated entirely from the data. These were then revised by merging and splitting codes. Links between the different codes were identified and cards were sorted into categories on the basis of similar meaning or concepts (*Appendix VII*). The themes that emerged from the list of categories were then considered in terms of previous research and existing theories.

The interviewees - descriptive data.

From the list of 29 partners who had volunteered to be interviewed, 10 were randomly chosen for interviews. Five of the interviewees were men, and five were women. The age of the interviewees ranged from 31 to 63 years, with an average age of 43.7 years. Six interviewees were in full time employment, two worked part time and two were full time carers for their wives. Interviewees were evenly distributed across the classifications for years spent in education, with three interviewees completing secondary education, three completing tertiary education, 2 being educated to a graduate level and two at a postgraduate level. The number

of years that interviewees had been in a relationship with their partners ranged from 4.5 to 32 years, giving a mean length of relationship of 16.65 years. Interviewees reported the duration of their partner's pain to range from 2 to 25 years, with average pain duration being 8 years. The severity of their partner's pain within the last two weeks using a 0-100 visual analogue scale reportedly ranged from 40-100, the average being 73.

Themes emerging from the interviews.

The interview codes used can be grouped into nine categories and the themes that emerged summarised into three main areas (see Table 13).

Table 13: Themes and categories used in the interview analysis.

<p>I. BELIEFS ABOUT PAIN & TREATMENT</p> <p>a) Beliefs about the pain Physical causes Vicious circles The condition being lived with The impossible cure A future of pain Uncontrollable pain?</p> <p>b) Medication Side effects of medication Tablets don't work</p> <p>II. CONSEQUENCES</p> <p>a) For the partner Accepting what they can't do. Emotional conflict There's nothing I can do Depression and emotional strain Consumption of time</p> <p>b) For the relationship Do I stay or do I go? Insecure future Being more realistic about the future Sex matters Social life and recreation Financial worries Role change Parenting Tip-toeing around Communication Making us closer</p>	<p>III. LIVING WITH THE CHRONIC PAIN.</p> <p>a) External and Internal Resources Positive attitude Faith/Hope Time to switch off. Family support Determination and inner strength Drugs and alcohol</p> <p>b) Knowledge and Information Being told too much Knowledge pursuits The unpredictability of never <u>really</u> knowing</p> <p>c) Coping + Learning new skills Fluctuating ability to cope Dealing with disappointments and set-backs Coping with additional stressors Taking one day at a time Learning to cope Knowing what not to do Adopting new strategies Adaptation Keeping busy Constant planning Not stepping in too quickly</p> <p>d) Looking forward Personal growth and new opportunity Making the most of life</p> <p>e) Experiences of services A disinterested NHS Mistakes and inefficiencies Given no answers Help, what help? Helping partners</p>
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These themes will now be considered, and the main categories outlined, with some of the original data given by the interviewees.

3.3.1 Beliefs about the Pain and its Treatment

All of the interviewees attributed the cause of their partner's pain to physical injury or illness e.g. accident or injury at home, work or from sport and infections/viruses. Partners shared a clear identity of the condition that they were living with, namely an ongoing but fluctuating condition that gave rise to all encompassing mobility problems (e.g. difficulties with walking, sitting, standing, lying down, driving, bending and lifting), functional difficulties, marked sleep disturbance, and emotional distress such as frustration, irritability, anxiety, depression and anger. 'K' reported that his wife was *"not able to move, and when she does she has a slow jerky movement. She's not able to sleep or roll over. She's not able to do the things she used to do, so she feels angry and frustrated"*. 'T' reported, *"night-time is the worst. He doesn't go up until he's absolutely exhausted because he knows he can't sleep. He'll get into bed for about an hour. Then he'll complain of painful joints. He'll do some stretches but his muscles will start to hurt, so he'll get up, have a drink, read a bit and then go back to bed. Another hour later he will be up again, and this goes on all night, most nights"*. 50% of the interviewees were also aware of their partner's increasing physical disability and the frustration and anger that often results, as they become less able at doing things they used to do.

An emergent story was the future of pain that partners were facing. 'B' reported, *"he'll be like he is for the rest of his life. It's not going to go away, particularly as the drugs don't help"*. Partners expressed a desire to see their spouses get better, but reported having to be realistic about the future of their condition: *"I'd like it to be better but if I'm honest I don't think it will be. He copes with it better and I can see that, but I can't imagine it ever going away. We will have to live with it"* ('S'). 'T' shared this view. *"this is it, this is as good as it gets"*.

Partners also reported there being no cure for the pain. The impossibility of a cure was attributed to the nature of the injury, personal characteristics of the patient or insufficient resources within current health provisions. Partners were mixed in their views as to whether the pain could be controlled. Some partners believed that their

spouses had no personal control of the pain (*"she has no control, none at all"* - 'JB'), whereas some partners distinguished between the controllability of the physical experience of pain compared to its emotional side (*"She can control some of the emotional side, so that she is less angry. Keeping herself busy is her way of controlling things"* - 'K'). In contrast, 'S' believed that her husband used his pain to gain control and power in their relationship. Partners generally reported that they themselves had little control over the pain, except for ensuring medication was taken, and helping with physiotherapy exercises and relaxation routines.

Partners expressed much concern about pain medication. A third of interviewees reported their partner's medication to be ineffective. Another third were concerned about the side effects of their medication.

3.3.2 The Consequences of Chronic Pain for Partners

Consequences for the partner

Over half the interviewees expressed difficulty in accepting their partners' loss of abilities within the home. For many partners, this caused an emotional conflict between being sympathetic and understanding towards their partners and coping with their own emotional distress, which they often found difficult to express. 'B' reported that her biggest challenge was *"not getting annoyed with him, and biting my tongue. It's not to do with how I feel about him. I know he can't do that, but sometimes I feel like why can't he do that? It's so frustrating"*. 'J' agreed: *"a lot of the time I wanted to scream and shout as well, but I knew had to be the strong one. I had to say, come on, lets brush it off and start again"*.

Every partner described living with someone with chronic pain as an emotional strain, which could lead to feelings of depression, exhaustion and anger: *"it can be very depressing...it kind of sucks all the energy out of you. It's draining and can get you down"* ('B'), *"when I go to bed to rest I don't rest. I'm worrying about her all the time. Will she be all right? It affects me mentally and physically. I get so tired. The house is like Forth Bridge, the work is never ending"* ('JB'). Many partners reported feeling helpless and distressed by their inability to get rid of or ease the pain, often wishing for a 'magic wand'.

Consequences for their relationship

Some partners reported feeling insecure about the future of their relationship. This stemmed from financial worry and from the emotional impact on the relationship. 'G' reported feeling frightened of 'losing' her husband to his depression. 'S' described how the pain changed her husband into a different person, to the point that she felt she'd lost the man she married and been bereaved. Several partners reported going through the decision making process of whether to remain in their relationship. For those partners who had not considered divorce or who remained certain of their relationship, there was a sense of having to be more realistic about the future, and re-thinking future goals and plans.

A picture that clearly emerged was that of changing roles. Interviewees reported a complicated process of stopping or adapting their work in order to care for their partners, or becoming the main breadwinner if their partner stopped work. Some of the female interviewees reported their husband's difficulty in accepting they were no longer working or the main income provider. *"we told him to give up, but it was very difficult. It took him 6 months to accept. He was losing a lot of business, using other men to do his work, which was costing us a lot of money. His confidence dropped and he was very difficult to live with, very moody and withdrawn. Finally he admitted he couldn't go on and that he'd have to give it up ... I watched a very confident individual who ran his own business go rapidly downhill"* ('J'). Similarly, some partners reported feeling bitter and resentful themselves about having to alter their careers, or take on different responsibilities. Linked to this whole emotional process was the reality of needing sufficient funds to keep going. Indeed seven partners reported marked financial difficulties as a consequence of the pain.

Clearly the chronic pain impacted on other roles within the relationship, such as parenting roles. 50% of interviewees reported becoming the 'primary caregiver' for their children because of their partner's pain. Some partners worried about the impact on the children and were anxious about not being good enough parents: *"I worry about the quality of care that he can give them and how much he can emotionally tolerate parenting them"* ('J').

All partners described a marked reduction in their social relationships. This included stopping recreational activities that had been undertaken together (e.g. walking, mountain climbing, bike riding, overseas travelling), and withdrawing from social interaction: *"We used to walk into the village and go to the pub, but he gets sick now. He can't be bothered, it's too painful and uncomfortable" ('G'), "...he doesn't want to go out anymore, so we don't socialise as much. I end up making lots of excuses for him, which is frustrating" ('S'), "...we don't do anything on our days off because he catches up in his sleep" ('J'), "...we used to love going to the Lakes, but that's all stopped. He's lucky if he can get to the letterbox up the road" ('B').* The unpredictability of the pain had particular impact on social activities as often arrangements are cancelled at the last minute. 50% of partners found this aspect of the pain difficult to live with and frustrating, when plans suddenly change because their partners were now 'not feeling up to it': *"The most difficult thing is understanding and accepting that if we want to do something, and she's happy doing it, at the last moment things might change" ('K'), "If someone says do you want to do this, then all I can say is we'll try" ('B').*

Many partners reported improved communication in the relationship, with more time being made to sit down and talk to each other, and to spend time together. Being honest and open was regarded as essential to this communication. Those interviewees whose partners had pain when they first met reported their partners trying to 'cover-up' and hide their pain, particularly in the early stages of their relationship for fear of being 'found out'. Partners reported 'tip-toeing around' to avoid disturbing their spouses if they were catching up on sleep and had only just got settled: *"He doesn't know that we do it, but the washing machine won't go on, we dash to the phone so it doesn't disturb him or we quickly answer the doorbell" ('T').* For most partners, the need to be honest and open with each other and to talk to each other about the pain had made their relationships stronger and brought them closer together: *"Her illness has made me love and appreciate her more. I appreciate the gift of someone being there more than I used to, the gift of love and of life, I suppose" ('JB').*

3.3.3 Partners' Experiences of Living with Chronic Pain

External and internal resources

Many partners highlighted the importance of internal resources in helping them to cope with living with someone with chronic pain. 70% of partners reported that having a 'positive approach to life' protected both themselves and their partners from the emotional consequences of pain. Partners also referred to 'inner strength' and 'determination' as something that helped them to cope: *"Watching it happen was hard, but we got through it. I was determined and we survived"* ('J'), *"It's made me more determined. Determined never to sink under it. I hadn't realised I was such strong person"* ('G'). Two partners also identified spiritual/religious beliefs and inner faith as important factors that helped them to cope and gave them 'hope' for future change.

For many partners, having time to 'switch off' was seen as essential. Work or personal interests provided this opportunity for partners: *"When I'm at work all day, I have a laugh with my colleagues. It's a whole different world because I'm not thinking about him so much. It's my way of switching off"* ('T'), *"You have to switch off. You need to detach. We do this automatically as part of our way of life – doing things together and separately"* ('N'). Ironically, partners also reported feeling guilty that they had this opportunity to switch off when often their partners didn't. Support from other family members was also identified as an important coping resource, along with alcohol and cannabis use.

Knowledge and information

Partners described a pursuit for knowledge and information about their partner's conditions as they had often been told very little or rarely been included in any treatment plans or discussions. Partners reported spending personal time in libraries or on the Internet finding more information about chronic pain and available services. In contrast one partner believed they had been given too much information and that his partner had deteriorated after being given a fuller picture of her condition.

Coping and learning new skills

A picture that emerged quite quickly from the interviews was one of partners learning to cope with the condition. Partners described this process occurring gradually over time, as they became more knowledgeable of the condition and of those aspects of the condition that their partner managed well and areas where their partner required more support/found more difficult. There was a sense that learning to cope also required a certain level of emotional processing and acceptance: *"We've gone through the worst parts now and have come out the other side... As the months and years go by it becomes more obvious that things are not going to improve and we will have to cope with it more in as many ways as possible"* ('N').

Partners reported a fluctuating ability to cope: *"I find that whilst most days I am motivated to cope with it, some days I just can't do it"* ('B'), *"There are times when even now I find it difficult to cope and I feel I could actually walk away"* ('K'). The ability to cope was often influenced by pain flare-ups or by additional stressors e.g. family traumas.

Partners reported benefiting emotionally by being flexible and adapting their lifestyle to cope with their partner's pain. This included changing the nature of their work, arranging flexible work shifts, or pursuing new interests and discovering new pleasures. For some partners, needing to adapt their way of life had opened up new opportunities that previously had been overlooked or denied. Being adaptable often required adopting new strategies for helping their partner manage their pain. Partners reported finding some of the strategies they had learnt from their partner's treatment programmes particularly helpful, such as planning and prioritising, pacing and relaxation.

Partners also reported not planning too far ahead but taking one day at a time: *"We try and cope with what's coming next year rather than looking too far ahead"* ('G'), *"We just take each day as it comes"* ('JB'). Keeping busy was also highlighted as a useful distraction both for the partners and the patients.

Looking forward

Some partners reported making the most of life whilst opportunities were still available to them, regardless of the pain. 'T' reported that she and her partner tried to live as normal a life as possible, which included riding their motorbikes, despite being in more pain afterwards. For 'T' the emotional benefits of doing something that they both loved far outweighed the physical cost at this stage in their lives. For others, adapting their life to accommodate their partner's pain had given them an opportunity to develop and grow personally: *"Having to give up work to care for my wife has in a way given me a chance to do things that I always wanted to do...I'm a happier person and a stronger person...Holistically it has helped me"* ('KB').

Experiences of services

Most partners experienced the NHS as being uninterested in their views. Partners reported trying to get involved in consultations or treatment but being made to feel unwelcome. Partners reported that this had been particularly difficult to cope with in the earlier stages of their partners' illness, as they were often needing answers and further information but found services were unwilling to provide these. Partners also presented a picture of most of the services received as inefficient and ineffective. Particular attention was drawn to medical errors or misdiagnoses: *"The first diagnosis they made was wrong and he had to go back for further x-rays. The consultants were unhelpful and lacking in care"* ('J'), *"the doctors were incompetent and the health authority seemed apathetic"*, ('K'), *"the assumption was that it was a slipped disc or something. She had two operations. It's now believed that these operations probably made things worse"* ('N').

Partner's also expressed frustration about not being given appropriate answers when they or their partners asked specific questions about the cause of the condition or about prognosis: *"We've been trying to find out the cause of her pain for a long time. We haven't had a clear definition from anybody exactly, just lots of scans and not much progress"* ('M'), *"It was frustrating when nobody would give us any answers. We never got a conclusion even after lots of appointments and scans and operations. And we are no nearer now to knowing what the problem is"* ('N').

When asked how partners could be helped by services, two main themes emerged: emotional support and information. There was a consensus amongst most partners that additional emotional support would have helped them. Some partners felt group support would have provided them with a valuable opportunity to share experiences with other chronic pain partners, helping to reduce their sense of isolation: *"I would find it helpful sharing my experiences with others in a supportive environment... I imagine that would be beneficial for those of us who feel quite isolated, and it would be an opportunity to share information"* ('M'). In contrast, other partners stressed the importance of having additional emotional support from pain specialists e.g. a specialist pain nurse. 'T' pointed out that consultant specialists often don't have time to spend with patients in ensuring they have a good understanding of their condition. Instead 'T' believed she would have been helped by *"someone you could ask questions to, and who could tell us "this is what you've got, this is how it's going to affect you, and this is what you can do to help"*.

Partners also requested more information and education. One partner suggested attending treatment programmes in order to learn more about how to support her partner in their treatment. Others stressed the importance of being made aware of the available support services as early as possible, particularly social services and information about entitlements and benefits.

4. DISCUSSION

4.1 Summary of Main Findings:

Hypothesis 1:

The psychosocial functioning and adjustment of partners to living with someone with chronic pain will be similar to that of partners living with other chronic illnesses.

- Evidence was found in part support of hypothesis 1.
- Chronic pain partners' showed poorer psychosocial adjustment and functioning in all areas than comparative groups, with the exclusion of their domestic environment and social relationships, where no significant difference was found between chronic pain partners and cancer patients in their level of adjustment in these two domains.

Hypothesis 2:

Partners' illness representations and coping behaviours will account for more of the variance in psychosocial adjustment than demographic and disease variables.

- Evidence was found in support of hypothesis 2.
- None of the demographic and disease variables significantly predicted chronic pain partners' psychosocial adjustment.
- In comparison partners' illness representations and coping behaviours significantly predicted psychological adjustment to chronic pain in partners' vocational environment ($R^2 = 39.1\%$), domestic environment ($R^2 = 42.4\%$), sexual relationships ($R^2 = 22.1\%$), family relationships ($R^2 = 32.1\%$) and levels of psychological distress ($R^2 = 39.9\%$) but not partners' social relationships.

Hypothesis 3:

Partners' illness representations will account for more of the variance in coping behaviours than demographic and disease variables.

- Evidence was found in support of hypothesis 3.
- None of the demographic and disease variables significantly predicted chronic pain partners' coping behaviours.
- Partner's illness representations significantly predicted the use of the following coping strategies by chronic pain partners: planning ($R^2 = 17.5\%$), seeking

instrumental support ($R^2 = 18.6\%$), seeking emotional support ($R^2 = 31.2\%$), suppression of competing activities ($R^2 = 19.3\%$), turning to religion ($R^2 = 23.7\%$), focusing on and venting of emotions ($R^2 = 17.1\%$), denial ($R^2 = 28.6\%$), mental disengagement ($R^2 = 22.5\%$) and behavioural disengagement ($R^2 = 26.4\%$), but not active coping, positive reinterpretation and growth, restraint coping, acceptance, alcohol and drug use or the use of humour.

Qualitative Analyses:

Three main themes emerged from the interview data, each theme consisting of a number of salient points or categories. The first theme centred on partner's beliefs about the pain. Partners attributed the pain to physical causes, perceived chronic pain to have a strong identity and perceived the pain as permanent and incurable, beyond the control of the patient or any treatment. Partners perceived medication to be ineffective and some believed it to be dangerous.

The second theme that emerged from the interviews centred on partners' perceptions of the consequences of chronic pain for themselves and for their relationship with the patients. Partners described being faced with an emotional conflict and the difficulty of accepting the patients' disabilities. They reported feeling depressed, emotionally strained and helpless. They described feeling insecure about the future of their relationships and reported a number of changes including additional roles and responsibilities and alternative life plans. Partners reported significant impact on their sexual relationships, their social and leisure activities and their financial circumstances. Some reported positive consequences such as improved communication and closer relationships.

The third theme that emerged centred on partners' experiences of living with someone with chronic pain. This incorporated five broad categories: external and internal resources, knowledge and information, coping and learning new skills, looking forward and experiences of services. Partners' suggestions for improving services were greater emotional support and more information.

4.2 Interpretation of Main Findings.

Hypothesis 1:

The psychosocial functioning and adjustment of partners to living with someone with chronic pain will be similar to that of partners living with other chronic illnesses.

Findings from this study indicated that living with someone with chronic pain was significantly associated with poor psychosocial functioning and adjustment in five areas of partners' lives measured: emotional well-being, physical health, relationships, occupation, and social activities. This is in keeping with previous studies of the effects of chronic pain on spouses (Schwartz, Slater, Birchler and Atkinson, 1991; Flor, Turk and Scholz, 1987; Snelling, 1994; and Ferrel, 1995). This is also in keeping with previous studies that have investigated the impact of other chronic illnesses on partners and carers (Orford, 1987; Ben-Zur et al, 2001; White and Grenyer, 1999). Barrowclough and Parle (1997) estimate that between 29% and 60% of schizophrenia carers suffer significant distress associated with their care-giving role. Stewart, Davidson, Meade, Hirth and Makrides's (2000) study of myocardial infarction survivors and their spouses found that spouses reported similar post-MI stresses that those of the actual survivors, namely emotional impact, lifestyle change and a search for information. Anxiety, depression, loss of intimacy and reduced opportunities for social and leisure activities have also been reported by carer of patients with motor neurone disease as consequences of their caring role (Goldstein et al, 1998).

Given the significant number of studies that highlight the impact of chronic illness on partners, therefore, the results of this study were not surprising. Perhaps more surprising, however, was that the findings indicated that the experience of living with someone with chronic pain had a great association with poor psychosocial functioning than the experience of partners living with someone with breast cancer (Holdaway, 2000). Furthermore chronic pain partners were found to have at least as poor, or if not poorer, adjustment than actual patients suffering from cancer (Derogatis and Derogatis, 1990). This is surprising given the nature and severity of cancer as an illness generally, and the huge social stigma that remains associated with the condition.

A possible explanation for these results may be that the participants were partners of a selected group of chronic pain patients, namely those receiving or awaiting treatment from community disability and rehabilitation services. This group of patients suffer from severely disabling chronic pain and may differ from the majority of chronic pain patients in the community who are not referred for treatment from rehabilitation services. It is possible, therefore, that the nature and severity of the chronic pain experienced by the patients in this study skewed the responses of their partners, such that the impact of the condition was as great or if not greater for chronic pain partners than cancer patients and breast cancer partners.

Hypothesis 2:

Partners' illness representations and coping behaviours will account for more of the variance in psychosocial adjustment than demographic and disease variables.

Findings from this study indicated that demographic and disease variables failed to account for more of the variance in psychosocial adjustment than partners' illness representations and coping behaviours. Even when entered collectively into a multiple regression equation the partner variables of age, gender, length of relationship, perceived pain duration and perceived pain severity failed to significantly predict partner's psychosocial adjustment.

In contrast all but one of the illness representation and coping multiple regression equations identified significant predictors. The illness representation attributes of identity, timeline (cyclical), control (treatment) and consequences, and the coping strategy behavioural disengagement, were negatively related to psychosocial adjustment. These findings provide evidence in support of the application of Leventhal's self-regulatory model and illness representation framework to partners. They are also in keeping with the few studies that have investigated the role of partner illness representations and coping behaviours in psychosocial functioning. Illness perception factor timeline and coping strategies 'venting of emotions' and 'suppression of competing activities' were found to predict carer distress in spouses of non-acute stroke patients (McClenahan and Weinman, 1998). Similarly, carer's perceptions of the consequences of schizophrenia for patients and themselves, and

a strong illness identity, were positively related to carer distress, depression and subjective burden (Barrowclough et al, 2001).

The illness representations and coping strategies of chronic pain partners failed to predict impact on their social activities. This suggests that other factors may be involved in the impact of chronic pain on partner's social activities. Many of the partners interviewed reported significant financial difficulties as a consequence of the chronic pain. They also reported a reduction in shared activities due to their partner's disabilities, and a reluctance to socialise without their partner because of guilty feelings. It is possible, therefore, that these may be significant factors influencing the impact of chronic pain on partners' social activities.

Hypothesis 3:

Partners' illness representations will account for more of the variance in coping behaviours than demographic and disease variables.

Findings from this study indicated that demographic and disease variables failed to account for more of the variance in coping than partners' illness representations. Even when entered collectively into a multiple regression equation, the partner variables of age, gender, length of relationship, perceived pain duration and perceived pain severity failed to significantly predict partner's coping strategies.

In contrast, findings of this study indicated partner's perceptions of chronic pain were positively related to some of their reported coping strategies, namely: planning, seeking instrumental support, seeking emotional support, suppression of competing activities, turning to religion, focusing on and venting of emotions, denial, mental disengagement and behavioural disengagement. All but perceptions of identity and illness coherence were predictive of coping. This provides some support for the application of an illness representation framework to coping in partners of chronic pain patients and possibly other chronically ill patients.

Unfortunately, to date there are no other studies that have used this framework to investigate the relationship between the partner illness representations and coping in other chronic conditions with which to compare these findings. However the

findings of this study are in keeping with other studies that have investigated the relationship between illness representations and coping in patients with chronic illness (Moss-Morris et al, 1996; Heijmans, 1998; Heijmans, 1999)

Active coping, positive reinterpretation and growth, restraint coping, acceptance, alcohol and drug use and the use of humour were not related to partner's illness representations in this study. This suggests that other factors than illness representations influenced these coping strategies. Overall, partner illness representations explained less of the variance in partner coping than in psychosocial adjustment and more of the variance in psychosocial functioning than coping behaviours. This suggests that other factors may be more important in explaining partners' coping, or indeed there may be other illness representations that this study has not measured which may be related to partners' coping behaviours. It also suggests that illness representations are stronger predictors for adjustment than coping. This finding is in contrast with the self-regulatory theory of Leventhal but is in agreement with the results of other researchers exploring the relationship between illness representations and coping in chronically ill patient groups. A study of multiple sclerosis by Earll and Johnston (1994) and Moss-Morris et al's (1996) study of chronic fatigue syndrome have shown illness representations to be superior to coping in predicting outcome. It has been suggested, however, that this may reflect the parallel processing of illness representations – the emotional responses of partners to chronic illness may in fact be more strongly linked to cognitions than coping because partners may be more limited in their coping options (Pimm, 1997).

An alternative explanation for the weaker association between coping and adjustment in this study may be to do with the way in which coping was measured. It might have been better to use more specific coping measures or to measure coping in behavioural terms rather than as general strategies. Coping strategies are only effective if they define and exhaust the major forms of coping used to deal with specific problems. If the scales overlook the key responses, the picture they present will be distorted (Leventhal and Nerenz, 1985).

Interview findings:

Partners' experiences of living with someone with chronic pain have already been summarised in the previous section. These findings can be compared to those of Mackay (1997) who used concept mapping with female spouses of chronic low back pain sufferers. Similar to this study, the spouses in Mackay's study reported feeling helpless and uncertain about the future, taking one day at a time, adapting their lifestyles and learning to do things differently. Furthermore, similar themes emerged from Snelling's (1994) study that used a grounded theory approach to interview the partners and children of chronic pain patients in an attempt to understand the effects of chronic pain on the family unit. Relationships of partners were significantly affected in terms of their marital partnership, sexual activity, contact with friends and relatives and their roles. This caused social isolation, role tension, marital conflict, reduced sexual activity and feelings of anger, anxiety, resentment and despondency. Also the extent to which chronic pain negatively affected partners depended on how effective the family was in coping.

4.3 Study Limitations

The generalisability and interpretation of these findings are limited by a number of methodological issues.

4.3.1 Sample

Firstly the small sample size ($n = 35$) means any conclusions drawn from this study must be interpreted with caution. Given the small sample size and the relatively large number of variables entered into the regression equations, there is an increased risk of Type 1 error (false positive). It must be pointed out, however, that all but two of the significant equations fell below the $p = 0.01$ level.

A larger sample size would have increased the power of statistical analyses and would have enabled the researcher to investigate clusters of illness representations and their effect on adjustment. This is felt to be particularly important as previous studies suggest a relationship between groups of illness representations, as opposed to individual representations and outcome (Heijmans, 1998).

The self-selection of participants also limits the interpretation of the findings in a number of ways. Firstly, there is no way of differentiating between partners who participated and those who chose not to. Thus important information is made unavailable. Secondly, it has already been mentioned that participants were the partners of a selected group of patients suffering from severely disabling chronic pain, such that they required interventions from community disability and rehabilitation services. Consequently, it is unlikely that the partner sample used were representative of the majority of partners who live with chronic pain sufferers. The latter typically manage their pain without seeking treatment or rehabilitation programmes. Despite this, however, patients with severe chronic pain are the main users of services and therefore it was felt to be particularly important to understand the experiences of this group of partners. It is quite possible, however, that given their reported experiences of services being uninterested in their views, the participants felt a particular need to have their experiences validated by this research, which may have affected their responses.

4.3.2 Measures

Two of the measures used (IPQ-R, PAIS-SR) had to be modified slightly and reworded for partners. It is possible that this may have affected the results and any comparisons to normative data using these measures. Furthermore not all the measures used in this study had been used specifically with chronic pain. This meant that normative chronic pain data was not available for some of the measures. However, all of the measures had been used by other chronic illness populations, thus comparisons were made to these other groups e.g. cancer patients and breast cancer partners.

4.3.3 Design

Another limitation of this study was the difficulty in trying to understand the complex processes underpinning the relationships between illness representations, coping and psychosocial adjustment through a cross-sectional design. Collecting data at only one point in time inhibited any investigation of the dynamic nature of illness perceptions or their role in adjustment to illness over time. Longitudinal studies are needed to confirm the association between illness representations, coping and psychosocial adjustment to illness over time.

The findings of this study suggested that demographic and disease variables do not predict psychosocial adjustment or coping in chronic pain partners. These findings need to be considered with caution as not all the demographic data collated were entered into the multiple regression analyses e.g. socio-economic class, educational years and employment status. This data did not meet the assumptions for parametric tests and thus could not be used in the multiple regression equations. It is possible therefore that socio-economic class, employment status and years spent in education may additionally explain some of the variance in partner's coping and psychosocial adjustment. Similarly this study can be criticised for not collecting ethnicity data, as ethnicity has been found to play a role in chronic pain perceptions (Bates, Edwards and Anderson (1993). In this study however, ethnicity is unlikely to be a significant factor as the population in the geographical area of the study is largely white European. This will, however, limit the generalisability of the findings to other ethnic groups.

4.3.4 Qualitative work

A number of methodological issues need to be considered when interpreting the qualitative data. Firstly, although partners were interviewed without the patients and were assured of the researcher's independence from the chronic pain management team at Rayner's Hedge, the design assumed that partners would trust the researcher to maintain their confidentiality. It is possible that this may have limited or influenced the comments they felt able to make, particularly for the partners of those patients currently receiving or awaiting treatment from Rayner's Hedge.

Secondly, the qualitative data was used to facilitate the interpretation of the quantitative data and met the objectives of the study, which was to understand more fully the experiences of chronic pain partners. The preliminary stages of a grounded theory approach were used to analyse this data, but due to time limitations, the data was not used to generate its own theory. In addition, the study can be criticised for using semi-structured interviews to gather qualitative data, which imposes a framework upon the interviews, and thus the data gathered, hence contradicting the main principles of a grounded theory approach.

Furthermore, an independent second rater was not used to check the reliability of the codes and categories created. The themes that emerged were also not validity checked by the participants, as recommended by Pidgeon and Henwood (1996). This was largely due to the strict time deadlines within which the study had to be completed, and because it was envisaged that the small number of interviews (n = 10) carried out in this study would be viewed by others as a preliminary stage in a larger qualitative study. With hindsight it is also acknowledged that collecting and analysing both quantitative and qualitative data was a huge undertaking in such a short time frame within which to complete the study, and it is recognised that the demands of each impacted on the researchers ability to conduct both parts of the study as thoroughly as might be desired e.g. the absence of triangulation.

4.4 Clinical Implications

The results of this and previous studies strongly suggest that chronic pain has a major impact on partners. This has important implications for clinical providers and services. The most obvious implication is that providers need to move away from a model of individual care and acknowledge that adjustment to chronic pain is not an individual but an interpersonal process. It would seem essential, therefore, that providers redesign their services to include the partners of chronic pain patients more, and be more partner-oriented. This involves consulting partners more about their needs, as well as those of the patient, and by undertaking more detailed partner assessments. Furthermore the challenge for services is to design and evaluate interventions targeted specifically towards helping partners adjust and cope with their experiences of living with someone with chronic pain.

The second significant finding from this study is that the degree of impact on partners is partly determined by partners' illness representations and coping. These findings challenge services, therefore, to design interventions that specifically target partners' perceptions of chronic pain and their coping procedures, in order to maximise their psychosocial functioning and minimise the impact of living with someone with chronic pain on partners.

These findings also have implications for health professionals and society more generally, as they highlight the importance of social context, particularly illness representations of others. This suggests that clinicians working with chronic pain patients and partners need to operate at the level of illness representations, including being aware of how their own perceptions of chronic pain and personal illness representations influence the way in which they work with their patients.

From the interviews chronic pain partners suggested a number of ways for improving services. In particular, partners requested easier access to more information. This could be achieved by involving partners more in services, in the ways previously mentioned, or it may be that partners might benefit from specific carer training. It is possible that a chronic pain partners support group could also be a useful resource for gaining information. Furthermore, a support group could provide partners with additional emotional support. Many partners reported that they were insufficiently emotionally supported by services, and felt that they would benefit from being able to share their experiences with other partners. The interviews also drew attention to the need of partners to be able to discuss their experiences on a more individual basis with someone who had more specialist knowledge of chronic pain yet could be more easily available than medical specialists. This could be achieved by appointing specialist pain nurses in pain clinics and management teams, perhaps with the specific remit of supporting and advising pain partners. Furthermore, services could help link partners to the support and information available from charities and voluntary agencies such as Back Care and Arthritis Care who have a wide range of easily available self-help resources e.g. books, magazines, videos and audio-tapes.

Perhaps a bigger but no less imperative challenge for services must be to change partner's perceptions of health services as being 'uninterested', 'inefficient' and 'ineffective'. This is a hard task to accomplish but is in keeping with the current NHS agenda and recent government initiatives that identify the support and training of carers as a key service objective. Specific questions need to be asked to clarify whether the uninterest and inefficiency stems from insufficient resources, poor staff morale, or a possible predominance of the medical model which focuses more on

searching for a cure rather than promoting more effective management of conditions.

4.5 Future Research

In order to build on existing research, it is essential to develop a theoretical model that offers an understanding of the dynamics of the relationship between illness representations, coping and adjustment in chronic pain partners. Longitudinal studies would be a first step towards such a model providing necessary information about the changing nature of illness representations and their relationship with coping and adjustment to chronic pain over time.

It is important that such future studies go beyond an individual model of illness representations to include those of partners. Furthermore as systemic theorists and a growing body of research suggests (Roberts and Connell, 2000), illness impacts on all individuals in the family including children. Future research should therefore aim to investigate the illness representations of other significant family members e.g. parents, siblings and children. Future studies need to explore both the role illness representations of family members play in their adjustment to illness, but also how their illness perceptions, coping and adjustment interacts with the illness perceptions, coping and adjustment of the individual.

As already mentioned, the processes underlying these interrelationships are hugely complex therefore the development of better measures may aid future investigations. This study used the IPQ-R to measure the illness representations of chronic pain partners. This relatively new measure (Moss-Morris et al, 2001) includes the five components of illness representation from the original IPQ along with three additional components. It is possible therefore, that there are other important illness representations that are not being targeted by existing measures. Further research may help to identify better ways of measuring important illness representations, and linking more closely with coping, emotional response and appraisals. Furthermore, experimental designs that manipulate the process e.g. interventions targeting illness representations, may be useful in evaluating by what, when and how change is affected.

Due to limitations of time this study undertook a preliminary exploration of partners' experiences of living with someone with chronic pain using a grounded theory approach. This exploration yielded interesting results and was important in that it offered the researcher an initial glimpse into the lives of chronic pain partners. It is hoped that future research will build upon the findings of this preliminary investigation to gain a fuller and more detailed understanding of the journey of partners through the chronic pain experience. It may also be useful to explore partners' experiences at an earlier stage of this journey.

4.6 Conclusion

In conclusion, evidence was found in support of the hypotheses. Chronic pain was found to be significantly associated with poor psychosocial adjustment and functioning in partners, at least as bad or if not worse than comparative groups. Partners' illness representations and coping behaviours were found to significantly predict partners' psychosocial adjustment in all areas of psychosocial functioning assessed except partners' social relationships. Partners' illness representations were also found to significantly predict partners' coping, although this relationship was less strong.

In a preliminary exploration of partners' experiences of living with someone with chronic pain, partners interviewed gave detailed accounts of how the pain impacted on their lives and how they coped.

Despite the limitations of this study, the findings have important clinical and theoretical implications. Firstly, they highlight the major impact of chronic pain on partners, which supports existing research and challenges services to change their current focus from an individual model of care to one that incorporates the opinions and needs of partners. Secondly, these findings support the application of the illness representation framework to partners' coping and adjustment to chronic pain, which challenges services to design and evaluate interventions targeted at partners' perceptions of illness. Thirdly, these findings highlight partners' needs for more information and additional emotional support.

Further work is needed however to better understand the complex processes underpinning illness representations and the impact of chronic pain on partners.

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6. APPENDICES

- I. Ethics approval letter
- II. Letter to patient's G.P's
- III. Questionnaire pack
- IV. Follow-up letter
- V. Interview schedule.
- VI. Example of interview coding card

Stoke Mandeville
Hospital NHS Trust

Buckinghamshire Health Authority

Aylesbury Vale Local Research Ethics Committee

Mandeville Road, Aylesbury
Buckinghamshire HP21 8AL
Telephone (01296) 315000
Direct Line: (01296) 316784

4th August 2000

Helen Waltier

Dear Ms Waltier,

Re: Project NC997 - Partners in pain: Investigating the relationship between illness perceptions, psychosocial adjustment and coping behaviours of those living with someone with chronic pain

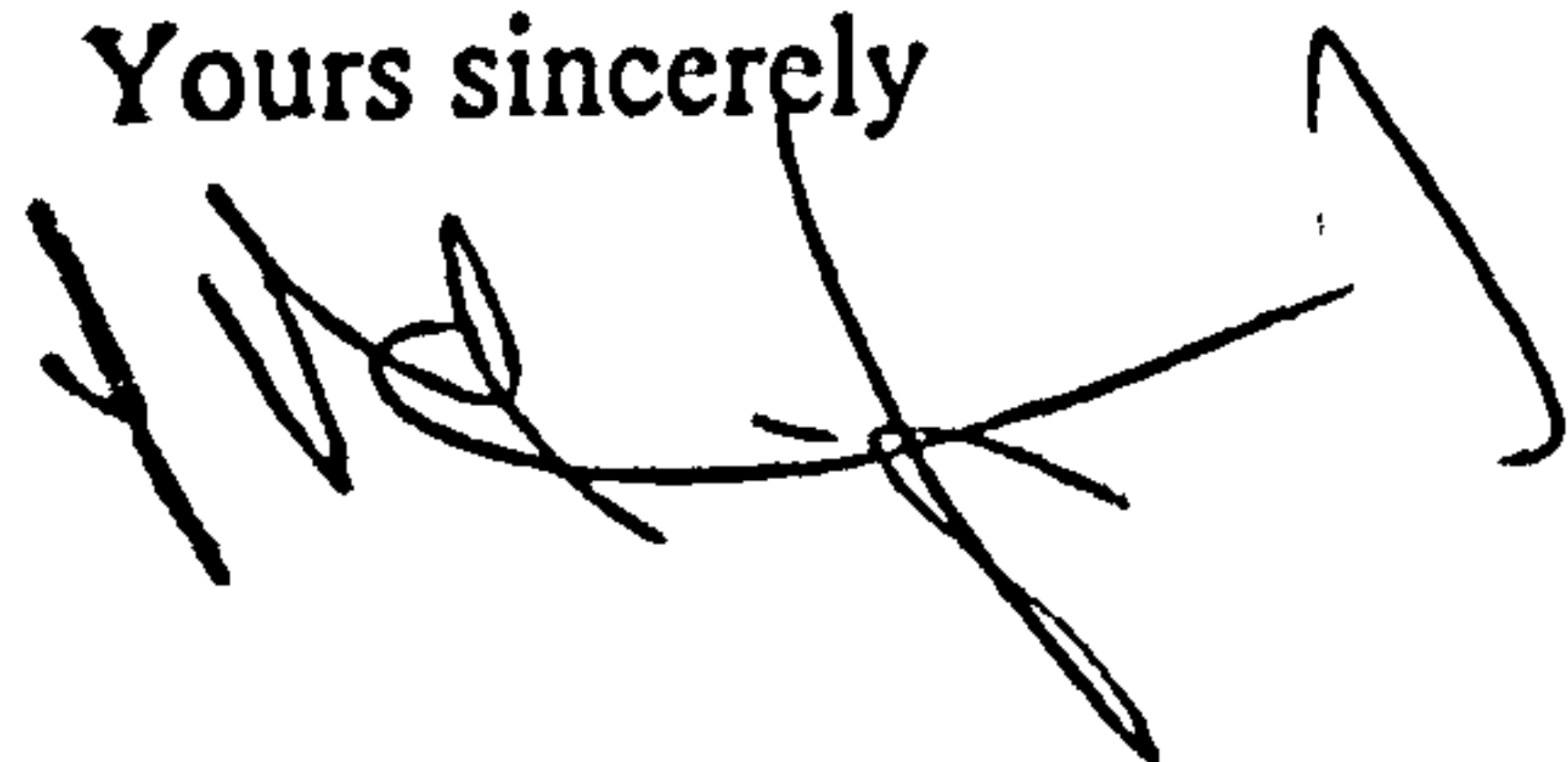
I refer to your application to the Local Research Ethics Committee for consideration of the above project. I am pleased to inform you that the Committee approves the project on ethical grounds on the understanding that:

- i. Any ethical problem, arising in the course of the project, will be reported to the Committee.
- ii. Any change in the protocol will be reported to the Committee.
- iii. The Data Protection Act 1984 be adhered to.
- iv. There is compliance, throughout the conduct of the study, with good clinical research practice.
- v. The Committee be informed if the research is discontinued for any reason.
- vi. A report be submitted after completion.
- vii. Ethical approval is for three years from the date of this letter

Ethical approval by the Committee is not an authority to proceed. You are advised to discuss your proposal with all heads of departments and others who might be affected, particularly if there are financial and/or staffing implications.

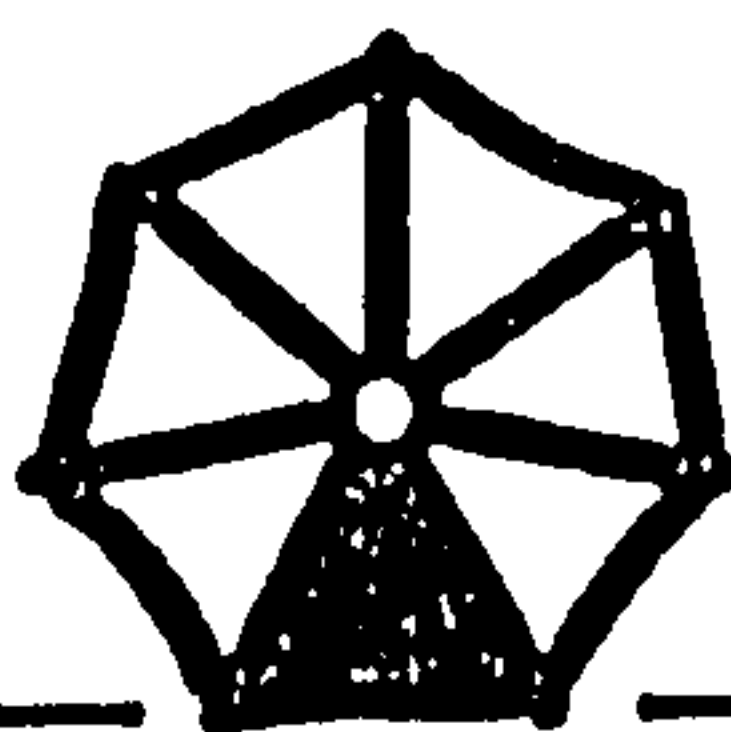
Please note that your research will be subject to review annually by the Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'P. Mansfield', written over the words 'Yours sincerely'.

PETER MANSFIELD

Secretary to Local Research Ethics Committee



Community Physical Rehabilitation Services

Aylesbury Vale Healthcare

Rayners Hedge, Croft Road, Aylesbury, Bucks. HP21 7RD .
Telephone: 01296 393319 Fax: 01296 392480

LETTER TO PATIENT'S G.P

Date:

Dear Dr.

Re: (Insert patients name, D.O.B, and address).

The above named patient and their partner have been invited to participate in a research study of the effects of chronic pain on partners. The study aims to explore the impact on partner's lives of living with someone with chronic pain.

The title of the research study is: *"Partners in pain: investigating the relationship between the illness perceptions, psychosocial adjustment and coping behaviours of those living with someone with chronic pain"*. The research is being carried out by Helen Waltier, Trainee Clinical Psychologist, as part of a dissertation project for the Oxford Doctorate in Clinical Psychology, and is being supervised by John Pimm, Consultant Clinical Psychologist, Rayner's Hedge, Aylesbury.

The first part of the research involves written questionnaires being completed by the partners of people who have chronic pain. The second part of the research involves partners being interviewed.

The research study is entirely voluntary, and any decision to participate or not in the study will not affect your patient's treatment in any way.

Your patient has been given a detailed information sheet of the study and has been asked to complete a written consent form if they are happy for their partners to participate.

If you have any queries regarding any of the above, or require further information, then please do not hesitate to contact us at either:

Rayner's Hedge
Croft Road
Aylesbury
Bucks
HP21 7RD
Tel: 01296 393319

or

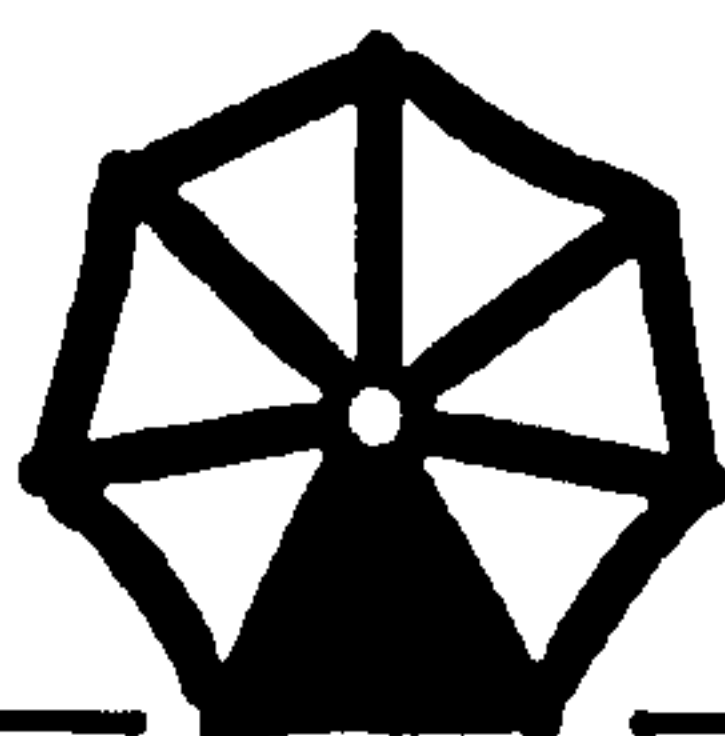
Oxford Doctorate in Clinical Psychology
ISIS Education Centre
Warneford Hospital
Oxford
OX3 7JX
Tel: 01865 226431

Yours sincerely,

Helen Waltier
Trainee Clinical Psychologist

John Pimm
Consultant Clinical Psychologist





Community Physical Rehabilitation Services

Aylesbury Vale Healthcare

Rayners Hedge, Croft Road, Aylesbury, Bucks. HP21 7RD

Telephone: 01296 393319 Fax: 01296 392480

Partners in Pain: Investigating the relationship between the illness perceptions, psychosocial adjustment and coping behaviours of those living with someone with chronic pain.

INFORMATION SHEET

We would like to invite you and your partner to take part in a research study. This information sheet tells you about the study. We are interested in looking at the effects of chronic pain on patient's partners, particularly the impact on partner's lives (e.g. their health, relationships, hobbies) of living with someone with chronic pain. As part of this study we would like to find out the ideas that partner's have about chronic pain. ***We would, therefore, be very grateful if you could pass this information onto your partner.*** If you currently do not have a partner, then please return this pack uncompleted.

The first part of the research involves written questionnaires being completed by partners (i.e. husbands, wives, spouses) of people who have chronic pain. The questionnaires will take approximately 40-50 minutes to fill in. The second part of the research involves partners being interviewed by Helen Waltier. Interviews will take place at Rayner's Hedge, Aylesbury or at your partner's home if preferred, and should take approximately 45 minutes. Additional time can be made available if help is needed to fill in the questionnaires.

This research study is **VOLUNTARY** and whether you take part is entirely your choice. If you decide not to be in the study, or drop-out at a later date, ***your treatment will not be affected in any way.*** We would also like to assure you that all information obtained will remain ***strictly confidential.*** Please feel free to ask any questions that you want about this research. Every effort will be made to answer your questions as best we can. If you do have any queries please ring Helen Waltier on 01296 393319 (Rayners Hedge) or 01865 226431 (Oxford Doctoral Course in Clinical Psychology).

If you are in agreement and your partner would like to take part in the first part of the study then:

- 1) you and your partner should sign the written consent form
- 2) your partner should fill in the attached questionnaires.
- 3) the questionnaires and signed consent form should be returned in the stamped addressed envelope provided.

If your partner also wishes to take part in the research interviews, then they should provide their contact details in the space provided on the consent form, in order that a suitable interview time can be arranged.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION

Helen Waltier
Trainee Clinical Psychologist

John Pimm (Research Supervisor)
Consultant Clinical Psychologist



**Partners in Pain: investigating the relationship between
the illness perceptions, psychosocial adjustment and coping behaviours
of those living with someone with chronic pain.**

CONSENT FORM.

1. PATIENT CONSENT

Please circle your answers

Have you read the Information Sheet ?	YES / NO
Do you understand the Information Sheet?	YES / NO
Have you had an opportunity to ask further questions about this study?	YES / NO
Have you received enough information about the study?	YES / NO
Do you understand that you are free to leave the study	YES / NO
- at any time?	
- without having to give reason for leaving?	
Do you agree to take part in the study?	YES / NO

Patient's signature:

Patient's name (block letters):

Date:

Name of Investigators: Helen Waltier, Trainee Clinical Psychologist
John Pimm, Consultant Clinical Psychologist.

2. PARTNER CONSENT

Please circle your answers

Have you read the Information Sheet ?	YES / NO
Do you understand the Information Sheet?	YES / NO
Have you had an opportunity to ask further questions about this study?	YES / NO
Have you received enough information about the study?	YES / NO
Do you understand that you are free to leave the study	YES / NO
- at any time?	
- without having to give reason for leaving?	
Do you agree to take part in the study?	YES / NO

Partner's signature:

Partner's name (block letters):

Date:

CONTACT DETAILS FOR PARTNER INTERVIEWS:

.....
.....
.....
.....
.....

Name of Investigators: Helen Waltier, Trainee Clinical Psychologist
John Pimm, Consultant Clinical Psychologist

ID NO: 34

CHRONIC PAIN PARTNER QUESTIONNAIRE SURVEY

Please enter your contact number in the box below (this will only be used for checking responses given):

Section A : INFORMATION ABOUT YOU

demo.dat

1.

Please enter your age (in years) in the box provided:
2.

Are you: (please circle appropriate response)

MALE / FEMALE
- 3a.

Please indicate your employment status by ticking the appropriate boxes:

I am currently in full-time employment

I am currently in part-time employment

I am currently unemployed and looking for work

I am currently unemployed but am not looking for work at the moment

I am currently in full-time education

I am retired from work

Other (please specify)

3b.

What is YOUR occupation?
(please enter in box provided)

3c.

What is YOUR PARTNER'S occupation?
(please enter in box provided.

4.

How many years have you spent in full-time education?
(please enter the number of years in the box provided)

5.

For how many years have you had a relationship with your partner?
(please enter the number of years in the box provided)

Section B : INFORMATION ABOUT YOUR PARTNER'S CHRONIC PAIN

6.

How long has your partner had chronic pain?
(please enter the number of years in the box provided)

7.

How bad do you feel your partner's chronic pain has been over the past few weeks?
(please put a cross on the line below to indicate your response)

no

0

100

worst pain

pain

imaginable

This questionnaire asks you for your views about aspects of your health. Answer every question by marking the answer as indicated. If you are unsure about how to answer, please give the best answer that you can.

1. In general, would you say your health is:
- (Circle one)
- Excellent.....

Very Good

Good

Fair

Poor

1

2

3

4

5

2. The following items are about activities you might do during a typical day. Does **your health** now limit you in these activities? If so, how much?
- (Circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf.	1	2	3
c. Lifting or carrying groceries.	1	2	3
d. Climbing several flights of stairs.	1	2	3
e. Climbing one flight of stairs.	1	2	3
f. Bending, kneeling or stooping.	1	2	3
g. Walking more than a mile.	1	2	3
h. Walking several blocks.	1	2	3
i. Walking one block.	1	2	3
j. Bathing or dressing yourself	1	2	3

We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer all the questions by circling the answer which you think most nearly applies to you. Remember we want to know about present and recent complaints, NOT those you had in the past.

Have you RECENTLY:

1.

Been feeling perfectly well and in good health?

Better than usual

Same as usual

Worse than usual

Much worse than usual
2.

Been feeling in need of a good tonic?

Not at all

No more than usual

Rather more than usual

Much more than usual
3.

Been feeling run down and out of sorts?

Not at all

No more than usual

Rather more than usual

Much more than usual
4.

Felt that you are ill?

Not at all

No more than usual

Rather more than usual

Much more than usual
5.

Been getting any pains in your head?

Not at all

No more than usual

Rather more than usual

Much more than usual
6.

Been getting a feeling of tightness or pressure in your head?

Not at all

No more than usual

Rather more than usual

Much more than usual
7.

Been having hot or cold spells?

Not at all

No more than usual

Rather more than usual

Much more than usual

Section E : YOUR VIEWS ABOUT YOUR PARTNER'S CHRONIC PAIN IPQ-R(CP)

Listed below are a number of symptoms that your partner may or may not have experienced since they developed their illness. Please indicate by circling Yes or No, whether you think they have experienced any of these symptoms since they developed their illness, and whether you believe that these symptoms are related to their chronic pain.

	They have experienced this symptom <i>since their illness</i>		This symptom is <i>related to their chronic pain</i>	
Pain	Yes	No	Yes	No
Sore Throat	Yes	No	Yes	No
Nausea	Yes	No	Yes	No
Breathlessness	Yes	No	Yes	No
Weight Loss	Yes	No	Yes	No
Fatigue	Yes	No	Yes	No
Stiff Joints	Yes	No	Yes	No
Sore Eyes	Yes	No	Yes	No
Wheeziness	Yes	No	Yes	No
Headaches	Yes	No	Yes	No
Upset Stomach	Yes	No	Yes	No
Sleep Difficulties	Yes	No	Yes	No
Dizziness	Yes	No	Yes	No
Loss of Strength	Yes	No	Yes	No

We are interested in your own personal views of how you now see your partner's chronic pain. Please indicate how much you agree or disagree with the following statements about your partner's chronic pain by ticking the appropriate box.

	VIEWES ABOUT THEIR PAIN	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	Their pain will last a short time					
IP2	Their pain is likely to be permanent rather than temporary					
IP3	Their pain will last for a long time					
IP4	Their pain will pass quickly					
IP5	I expect that they will have this pain for the rest of their life					
IP6	Their pain is a serious condition					
IP7	Their pain has major consequences for their life					
IP8	Their pain does not have much effect on their life					
IP9	Their pain strongly affects the way others see them					
IP10	Their pain has serious financial consequences					

	VIEWS ABOUT THEIR PAIN	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP11	Their pain causes difficulties for those who are close to them					
IP12	There is a lot which they can do to control their symptoms					
IP13	What my partner does can determine whether their pain gets better or worse					
IP14	The course of their pain depends on them					
IP15*	Nothing my partner does will affect their pain					
IP16	They have the power to influence their pain					
IP17*	Their actions will have no affect on the outcome of their pain					
IP18*	Their pain will improve in time					
IP19*	There is very little that can be done to improve their pain					
IP20	Their treatment will be effective in curing their pain					
IP21	The negative effects of their pain can be prevented (avoided) by their treatment					
IP22	Their treatment can control their pain					
IP23*	There is nothing which can help their pain					
IP24	The symptoms of their pain are puzzling to me					
IP25	Their pain is a mystery to me					
IP26	I don't understand their pain					
IP27	Their pain doesn't make any sense to me					
IP28*	I have a clear picture or understanding of their pain					
IP29	The symptoms of their illness change a great deal from day to day					
IP30	Their symptoms come and go in cycles					
IP31	Their illness is very unpredictable					
IP32	They go through cycles in which their symptoms get better and worse.					
IP33	My partner gets depressed when they think about their pain					
IP34	When my partner thinks about their pain they get upset					
IP35	My partners pain makes them feel angry					
IP36*	My partners pain does not worry them					
IP37	Having this pain makes my partner feel anxious					
IP38	My partners pain makes them feel afraid					

CAUSES OF THEIR CHRONIC PAIN

We are interested in what you consider may have been the cause of your partner's chronic pain. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused their pain rather than what others, including doctors, may have suggested to you. Below is a list of possible causes for their pain. Please indicate how much you agree or disagree that they were causes for your partner's pain by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in their family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in their past					
C7	Pollution in the environment					
C8	Their own behaviour					
C9	Their mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused their pain					
C11	Overwork					
C12	Their emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Their personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused **THEIR CHRONIC PAIN**. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes of their chronic pain are:-

1. _____
2. _____
3. _____

THE EFFECTS OF YOUR PARTNER'S CHRONIC PAIN ON YOU

INSTRUCTIONS: The following questions are concerned with the effects that your partner's chronic pain has had on YOU. We are interested in knowing what effects it has had on your relationships and your ability to perform at home and work. We would also like to know about the effects on family and personal relationships. Other questions concern its effects on your social and leisure time activities, and how you have felt emotionally.

In answering each question, please put a tick in the box alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience that you have had.

Please answer the questions according to your experience within the past 30 days, including today. Some questions may not be applicable to you, in which case please leave them blank.

Part I asks questions about your job performance. If you have either full-time or substantial part-time employment, please answer in terms of your job. If you are primarily a student, please answer in terms of your academic work. If you are a housewife/husband, please answer as though your housework, neighbours etc. are your work environment.

PART I

- (1) Has your partner's chronic pain interfered with your ability to do your job (studies/housework)?
 - ☐ a) No problems with my job
 - ☐ b) Some problems, but only minor ones
 - ☐ c) Some serious problems
 - ☐ d) Their pain has totally prevented me from doing my job
- (2) How well do you physically perform your job (studies/housework) now?
 - ☐ a) Poorly
 - ☐ b) Not too well
 - ☐ c) Adequately
 - ☐ d) Very well
- (3) During the past 30 days, have you lost any time at work (studies/housework) due to your partner's pain?
 - ☐ a) 3 days or less
 - ☐ b) 1 week
 - ☐ c) 2 weeks
 - ☐ d) More than 2 weeks
- (4) Is your job (studies/housework) as important to you now as it was before your partner developed pain?
 - ☐ a) Little or no importance to me now
 - ☐ b) A lot less important
 - ☐ c) Slightly less important
 - ☐ d) Equal or greater importance than before
- (5) Have you had to change your goals concerning your job (education/domestic plans) as a result of their chronic pain?
 - ☐ a) My goals are unchanged
 - ☐ b) There has been a slight change in my goals
 - ☐ c) My goals have changed quite a bit
 - ☐ d) I have changed my goals completely

- (6) Have you noticed any increase in problems with your co-workers (student, neighbours) since they developed pain?**
- ☐ a) A great increase in problems
 - ☐ b) A moderate increase in problems
 - ☐ c) A slight increase in problems
 - ☐ d) None

PART II

- (1) How would you describe your relationship with your partner since they developed chronic pain?**
- ☐ a) Good
 - ☐ b) Fair
 - ☐ c) Poor
 - ☐ d) Very Poor
- (2) How would you describe your general relationships with other people you live with (e.g. children, parents etc.)?**
- ☐ a) Very Poor
 - ☐ b) Poor
 - ☐ c) Fair
 - ☐ d) Good
- (3) How much has your partner's chronic pain interfered with your work and duties around the house?**
- ☐ a) Not at all
 - ☐ b) Slight problems, easily overcome
 - ☐ c) Moderate problems, not all of which can be overcome
 - ☐ d) Severe difficulties with household duties
- (4) In those areas where their chronic pain has caused problems with your household work, how has the family shifted duties to help you out?**
- ☐ a) The family has not been able to help out at all
 - ☐ b) The family has tried to help but many things are left undone
 - ☐ c) The family has done well except for a few minor things
 - ☐ d) No problem
- (5) Has your partner's chronic pain resulted in a decrease in communication between you both?**
- ☐ a) No decrease in communication
 - ☐ b) A slight decrease in communication
 - ☐ c) Communication has decreased, and I feel somewhat withdrawn from them
 - ☐ d) Communication has decreased a lot, and I feel very alone
- (6) Some people in your situation (living with someone with an illness) feel they need help from other people (friends, neighbours, family etc) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?**
- ☐ a) I really need help but seldom is anyone around to help
 - ☐ b) I get some help, but I can't count on it all the time
 - ☐ c) I don't get all the help I need all of the time, but most of the time help is there when I need it
 - ☐ d) I don't feel I need such help, or the help I need is available from family and friends.

(7) Have you experienced any physical disability as a result of your partners pain?

- ☐ a) No physical disability
- ☐ b) A slight physical disability
- ☐ c) A moderate physical disability
- ☐ d) A severe physical disability

(8) A condition such as your partners can sometimes cause a drain on the family's finances: are you having any difficulties meeting the financial demands of their pain?

- ☐ a) Severe financial hardship
- ☐ b) Moderate financial problems
- ☐ c) A slight financial drain
- ☐ d) No money problems

PART III

(1) Sometimes having a condition like your partner's can cause problems in a relationship. Has your partner's pain led to any problems with your relationship?

- ☐ a) There has been no change in our relationship
- ☐ b) We are a little less close
- ☐ c) We are definitely less close
- ☐ d) We have had serious problems or a break in our relationship

(2) Sometimes people who live with somebody who is ill report a loss of interest in sexual activities. Have you experienced less sexual interest since your partner developed chronic pain?

- ☐ a) Absolutely no sexual interest
- ☐ b) A marked loss of sexual interest
- ☐ c) A slight loss of sexual interest
- ☐ d) No loss of sexual interest

(3) Illness sometimes causes a decrease in sexual activity. Has your relationship experienced any decrease in the frequency of sexual activities?

- ☐ a) No decrease in sexual activities
- ☐ b) Slight decrease in sexual activities
- ☐ c) Marked decrease in sexual activities
- ☐ d) Sexual activities have stopped

(4) Has there been any change in the pleasure or satisfaction that you normally experience from your sexual relationship?

- ☐ a) Sexual pleasure and satisfaction have stopped
- ☐ b) A marked loss of sexual pleasure or satisfaction
- ☐ c) A slight loss of sexual pleasure or satisfaction
- ☐ d) No change in sexual satisfaction

(5) Sometimes a condition like chronic pain will interfere with a couple's ability to perform sexual activities even though the person is still interested in sex. Has this happened to you and your partner, and if so, to what degree?

- ☐ a) No change in ability to have sex
- ☐ b) Slight problems with sexual performance
- ☐ c) Constant sexual performance problems
- ☐ d) Totally unable to perform sexually

(6) Sometimes an illness will interfere with a couple's normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?

- ☐ a) Constant arguments
- ☐ b) Frequent arguments
- ☐ c) Some arguments
- ☐ d) No arguments

PART IV

(1) Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your partner developed chronic pain?

- ☐ a) Contact is the same or greater
- ☐ b) Contact is slightly less
- ☐ c) Contact is markedly less
- ☐ d) No contact

(2) Have you remained as interested in getting together with these members of your family since your partner developed chronic pain?

- ☐ a) Little or no interest in getting together with them
- ☐ b) Interest is a lot less than before
- ☐ c) Interest is slightly less
- ☐ d) Interest is the same or greater than before

(3) Sometimes, when you are living with somebody who's ill, you are forced to depend on members of the family outside your household for physical help. Do you need physical help from them and do they supply the help they need?

- ☐ a) I need no help, or I am given all the help I need
- ☐ b) Their help is enough, except for some minor things
- ☐ c) They give me some help but not enough
- ☐ d) They give me little or no help even though I need a great deal.

(4) Some people socialise a great deal with members of their family outside their immediate household. Do you do much socialising with these family members, and has your partner's pain reduced such socialising?

- ☐ a) Socialising with them has been pretty much eliminated
- ☐ b) Socialising with them has been reduced significantly
- ☐ c) Socialising with them had been reduced somewhat
- ☐ d) Socialising with them has been pretty much unaffected, or we have never done much socialising of this kind

(5) In general, how have you been getting along with these members of your family recently?

- ☐ a) Good
- ☐ b) Fair
- ☐ c) Poor
- ☐ d) Very poor

PART V

- (1) **Are you still as interested in your leisure activities and hobbies as you were prior to your partner's chronic pain?**
- ☐ a) Same level of interest as previously
 - ☐ b) Slightly less interest than before
 - ☐ c) Significantly less interest than before
 - ☐ d) Little or no interest remaining
- (2) **How about actual participation? Are you still actively involved in doing these activities?**
- ☐ a) Little or no participation at present
 - ☐ b) Participation reduced significantly
 - ☐ c) Participation reduced slightly
 - ☐ d) Participation remains unchanged
- (3) **Are you as interested in leisure activities with your family (i.e. playing cards and games, taking trips, going swimming etc.) as you were prior to your partner's pain?**
- ☐ a) Same level of interest as previously
 - ☐ b) Slightly less interest than before
 - ☐ c) Significantly less interest than before
 - ☐ d) Little or no interest remaining
- (4) **Do you still participate in those activities to the same degree you once did?**
- ☐ a) Little or no participation at present
 - ☐ b) Participation reduced significantly
 - ☐ c) Participation reduced slightly
 - ☐ d) Participation remains unchanged
- (5) **Have you maintained your interest in social activities since your partner's pain (e.g. social clubs, church groups, going to the movies etc.)?**
- ☐ a) Same level of interest as previously
 - ☐ b) Slightly less interest than before
 - ☐ c) Significantly less interest than before
 - ☐ d) Little or no interest remaining
- (6) **How about participation? Do you still go out with your friends and do those things?**
- ☐ a) Little or no participation at present
 - ☐ b) Participation reduced significantly
 - ☐ c) Participation reduced slightly
 - ☐ d) Participation remains unchanged

PART VI

(1) Recently, have you felt afraid, tense, nervous or anxious?

☐ a) Not at all ☐ b) A little bit ☐ c) Quite a bit ☐ d) Extremely

(2) Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?

☐ a) Extremely ☐ b) Quite a bit ☐ c) A little bit ☐ d) Not at all

(3) Recently, have you felt angry, irritable, or had difficulty controlling your temper?

☐ a) Not at all ☐ b) A little bit ☐ c) Quite a bit ☐ d) Extremely

(4) Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?

☐ a) Extremely ☐ b) Quite a bit ☐ c) A little bit ☐ d) Not at all

(5) Recently, have you worried much about your partner's pain or other matters?

☐ a) Not at all ☐ b) A little bit ☐ c) Quite a bit ☐ d) Extremely

(6) Recently, have you been feeling down on yourself or less valuable as a person?

☐ a) Extremely ☐ b) Quite a bit ☐ c) A little bit ☐ d) Not at all

(7) Recently, have you been feeling less attractive?

☐ a) Not at all ☐ b) A little bit ☐ c) Quite a bit ☐ d) Extremely

COPING WITH YOUR PARTNER'S CHRONIC PAIN

INSTRUCTIONS: We are interested in how you respond to your partners chronic pain. There are lots of ways to try and deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stress *as a result of living with someone with chronic pain*.

Think about your partner's chronic pain and how you have reacted to it. Then indicate the extent to which you do whatever each statement says, using the response choices listed just below:

- 1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

Please answer every item by entering your chosen response in the boxes provided. There are no 'right' or 'wrong' answers, so choose the answer most accurate for YOU - not what you think most people would say or do. Indicate what YOU usually do in response to your partner's chronic pain.

- ☐ 1. I try to grow as a person as a result of the experience
- ☐ 2. I turn to work or substitute other activities to take my mind off things
- ☐ 3. I get upset and let my emotions out.
- ☐ 4. I try to get advice from someone about what to do.
- ☐ 5. I concentrate my efforts on doing something about it.
- ☐ 6. I say to myself "this isn't real".
- ☐ 7. I put my trust in God.
- ☐ 8. I laugh about the situation.
- ☐ 9. I admit to myself that I can't deal with it, and give up quickly.
- ☐ 10. I restrain myself from doing anything too quickly.
- ☐ 11. I discuss my feelings with someone.
- ☐ 12. I use alcohol or drugs to make myself feel better.
- ☐ 13. I get used to the idea that it has happened.
- ☐ 14. I talk to someone to find out more about the situation.
- ☐ 15. I keep myself from getting distracted by other thoughts or activities.
- ☐ 16. I daydream about things other than this.
- ☐ 17. I get upset, and am really aware of it.
- ☐ 18. I seek God's help.
- ☐ 19. I make a plan of action.
- ☐ 20. I make jokes about it.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

- ☐ 21. I accept that this has happened and that it can't be changed.
- ☐ 22. I hold off doing anything about it until the situation permits.
- ☐ 23. I try to get emotional support from friends and relatives.
- ☐ 24. I just give up trying to reach my goal.
- ☐ 25. I take additional action to try to get rid of the problem
- ☐ 26. I try to lose myself for a while by drinking alcohol or taking drugs.
- ☐ 27. I refuse to believe that it has happened
- ☐ 28. I let my feelings out.
- ☐ 29. I try to see it in a different light to make it seem more positive.
- ☐ 30. I talk to someone who could do something concrete about the problem.

- ☐ 31. I sleep more than usual.
- ☐ 32. I try to come up with a strategy about what to do.
- ☐ 33. I focus on dealing with this problem, and if necessary, let other things slide a little.
- ☐ 34. I get sympathy and understanding from someone.
- ☐ 35. I drink alcohol or take drugs, in order to think about it less.
- ☐ 36. I kid around about it.
- ☐ 37. I give up the attempt to get what I want.
- ☐ 38. I look for something good in what is happening.
- ☐ 39. I think about how I might best handle the problem.
- ☐ 40. I pretend that it hasn't really happened.

- ☐ 41. I make sure not to make matters worse by acting too soon.
- ☐ 42. I try hard to prevent other things from interfering with my efforts at dealing with this.
- ☐ 43. I go to the cinema or watch television, to think about it less.
- ☐ 44. I accept the reality of the fact that it happened.
- ☐ 45. I ask people who have had similar experiences what they did.
- ☐ 46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

- ☐ 47. I take direct action to get around the problem.
- ☐ 48. I try to find comfort in my religion.
- ☐ 49. I force myself to wait for the right time to do something.
- ☐ 50. I make fun of the situation.
- ☐ 51. I reduce the amount of effort I'm putting into solving the problem.
- ☐ 52. I talk to someone about how I feel.
- ☐ 53. I use alcohol or drugs to help me get through it.
- ☐ 54. I learn to live with it.
- ☐ 55. I put aside other activities in order to concentrate on this.
- ☐ 56. I think hard about what steps to take.
- ☐ 57. I act as though it hasn't happened.
- ☐ 58. I do what has to be done, one step at a time.
- ☐ 59. I learn something from the experience.
- ☐ 60. I pray more than usual.

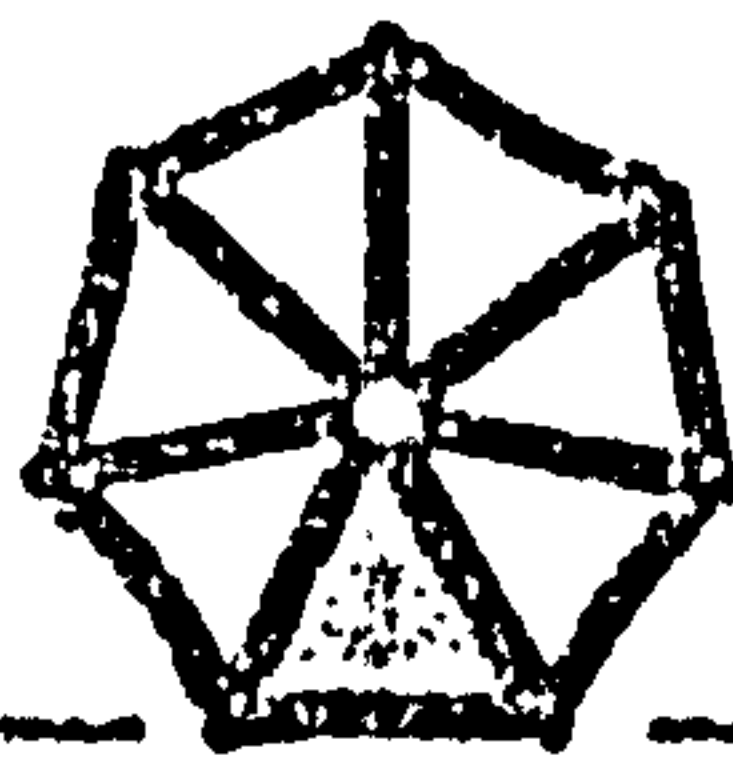
***This is the last page of the survey
THANKYOU for taking the time to fill in these questionnaires.***

Please return your completed questionnaires in the envelope provided to:

*Helen Waltier
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital
OXFORD OX3 7JX*

PLEASE RETURN BY: 15th DECEMBER 2000.

NOTE: Please remember to include your contact details and consent form if you are willing to take part in the research interviews



Community Physical Rehabilitation Services

Aylsbury Vale Healthcare

Rayners Hedge, Croft Road, Aylesbury, Bucks. HP21 7RD
Telephone: 01296 393319 Fax: 01296 392480

Partners In Pain: investigating the relationship between the illness perceptions, psychosocial adjustment and coping behaviours of those living with someone with chronic pain.

FOLLOW-UP LETTER

Two months ago we wrote to you to invite you and your partner to take part in a research study. We are writing again to repeat our invitation to you, as we would like to ensure that we have heard as many views and ideas from partners of people with chronic pain as we possibly can. Your participation would be greatly appreciated. *If you have already responded to our initial invite then please ignore this letter.*

We are interested in looking at the effects of chronic pain on patient's partners, particularly the impact on partner's lives of living with someone with chronic pain. We would, therefore, be very grateful if you could pass this information onto your partner. *If you currently do not have a partner, then please return this pack uncompleted.*

The first part of the research involves questionnaires being completed by partners (i.e. husbands, wives, spouses) of people who have chronic pain. The questionnaires will take approximately 40-50 minutes to fill in. *We would be particularly grateful if your partner would complete the questionnaires. Further copies of the questionnaires can be sent out to you upon request.* The second part of the research involves partners being interviewed by Helen Waltier. Interviews will take place at Rayner's Hedge, Aylesbury or at your partner's home if preferred, and should take approximately 50 minutes.

This research study is voluntary and *your treatment will not be affected in any way.* We would again like to assure you that all information obtained would remain *strictly confidential.* If you have any queries then please contact:

Helen Waltier on 01296 393319 (Rayners Hedge)
01865 226431 (Oxford Doctoral Course in Clinical Psychology).

If you and your partner would like to take part in the first part of the study then:

- 1) you and your partner should sign the written consent form.
- 2) your partner should complete the questionnaires.
- 3) the questionnaires and signed consent form should be returned to the address provided.

If your partner also wishes to take part in the research interviews, then they should provide their contact details in the space provided on the consent form, in order that a suitable interview time can be arranged.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION

Helen Waltier
Trainee Clinical Psychologist

John Pimm (Research Supervisor)
Consultant Clinical Psychologist



APPENDIX V.

Semi-structured interview schedule

ID NO:

Enter demographic data from questionnaires, and check during interviews

1. Age (in years):

2. Gender: MALE / FEMALE

3. Occupation: Yours?

Your partners?

full-time employment
part-time employment
unemployed - seeking
unemployed - not seeking
full-time education
retired
other

4. Educational history - years spent in formal education:

0-7 years (e. g. primary)
8-12 years (e.g. secondary)
13-14 years (e.g. A' levels)
15-17 years (e.g. degree)
18+ years (e.g. post-grad. studies)

5. Length of relationship (in years) with partner:

6. Duration of partner's CP (in years):

7. Severity of pain - how bad has partner's pain been in past few weeks?

no pain 0 _____ 100 worst pain imaginable

We'd like to understand what the experience of living with someone with chronic pain has been like for you

A) Questions about Identity

Thinking back to when your partner first developed chronic pain, can you remember what symptoms they had?
What do you feel are the main symptoms of their chronic pain now?

B) Questions about Cause

What do you think caused your partner's chronic pain?

C) Questions about Time-line

*How long do you think your partner's chronic pain will last?
Looking ahead, how do you think their illness will be?*

D) Questions about Control/Cure

*Do you think there will ever be a cure for their chronic pain?
If yes, have you any ideas what the cure might be?
How much control do you feel that they have over their pain?
How much control do you feel that you have over their chronic pain?*

E) Questions about Consequences

*In what ways has your partner's chronic pain affected your life?
What areas of your life have been most affected by your partner's pain?
What areas have been least affected?
What do you think has been the most difficult thing for you to cope with?*

F) Questions re relationship

*In what ways has your partner's CP affected your relationship?
Positive:
Negative:
How has your partner's CP affected your hopes re your future together?*

G) Questions about Coping

*What helps you to cope with living with someone with chronic pain?
What has been most supportive to you?
What is your experience of the help you have received from:
 the NHS?
 other agencies (i.e. social services)?
What do you think could be done to help you more?*

H) Additional comments –

Is there anything else you would like to say about your experience of living with someone with chronic pain?

APPENDIX VI

EXAMPLE OF INTERVIEW CODING CARD

Code = "Mistakes and Inefficiencies"

His ankle was operated on to sort it out but they missed a bone, which was not spotted for six weeks until the consultant saw the x-ray. He'd been complaining of pain and we'd been back to casualty but they still didn't notice it. When the consultant saw it he had him straight back in and operated to put it right ... and that was another lot of infection. He was in and out of hospital from June until March ('G', para.1).

We got irate with ourselves, with society and with the system and how it is run. We could do better ourselves ('JB', para.4).

The first diagnosis they made was wrong, and he had to go back for further x-rays. The consultants were unhelpful and lacking in care ('J', para.36).

The doctors were incompetent and the health authority seemed apathetic ('K', para.2).

It was diagnosed as one kind of arthritis and now we've been told it's another. The specialist she first saw was equally confused as to what it was ('M', para.7).

The assumption was that it was a slipped disc or something. She had two big operations. It's now believed that these operations probably have made things worse ('N', para.2).

Initially, when D was very ill and was sent out of hospital, there was very little aftercare. I was still working in London and he just wasn't coping at home. There wasn't enough support for him when we were both adjusting to the illness. I got quite ill and wasn't coping. I had to be signed off sick with a breakdown ('S', para.26).